EXPLORING HOW FAMILY MEMBERS EXPERIENCE MEDICAL ASSISTANCE IN DYING (MAiD)

by

KELLY C. H. SCHUTT

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ABSTRACT

This study explored how family members experience Medical Assistance in Dying (MAiD), since the 2016 Canadian legislation. The *Listening Guide*, a qualitative research methodology, was used to hear the experiences of seven family members from across Canada, whose loved one received MAiD. Analyses revealed that family members experienced tension in negotiating relationship to themselves, to their loved one, and to others involved. These tensions were heard in four voices throughout the study: witnessing, caregiving, honouring choice and supporting dignity, and surrendering and letting go.

Current procedures and policies tend to focus on the individual receiving MAiD. Shifting practices to align with relational ethics could challenge healthcare providers to consider how they might support family members. By acknowledging the social context of the patient receiving MAiD, this study extends the discourse surrounding MAiD beyond the realm of individual autonomy, suggesting a shift in care from being patient-focused to being truly *person-centred*.

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May this project serve its purpose: to honour the complex experiences of family members whose loved one has received MAiD.

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CHAPTER ONE: INTRODUCTION AND BACKGROUND

After advice and consent from the Senate and the House of Commons of Canada, Bill C-14 passed into legislation on June 17, 2016, allowing for Medical Assistance in Dying (MAiD) across Canada. This bill was enacted in response to the Supreme Court of Canada's decision in the *Carter v. Canada* (2015) case, which struck down Criminal Code provisions that had previously prevented the right to an assisted death. With Bill C-14 "persons who have a grievous and irremediable medical condition that causes them enduring and intolerable suffering and wish to seek [MAiD]" can receive treatment without financial cost, if they are deemed to be "competent adults whose deaths are reasonably foreseeable" (Parliament of Canada, 2016). Proponents of MAiD legislation argue that Bill C-14 protects the rights of Canadians to experience a dignified, peaceful death, instead of enduring ongoing suffering. Whereas prior to Bill C-14 it was illegal to consent to have death inflicted on oneself, counsel a person to die by suicide, or assist a person to die by suicide, Canadians can now legally receive or provide MAiD if eligibility criteria are met and if safeguards are ensured (Parliament of Canada, 2016).

With the implementation of Bill C-14, procedures and supports are being put in place across Canada. Research related to MAiD is in its infancy, and although some research has addressed the impact of MAiD on professional caregivers, at the time of this thesis being proposed, no research had yet addressed the experience of family members. The intent of the thesis, was, therefore, to explore how family members experience MAiD and to consider implications for healthcare professionals, including nurses.

Background

In order to understand the experience of family members whose loved one has received MAiD, the following section provides a background to Bill C-14, offering a necessary exploration of the sociocultural and political context surrounding MAiD. This involves first looking at how nurses have been involved with the legislation and implementation of MAiD, and second, considering relevant statistics demonstrating how Canadians have responded to the legalization of MAiD. Finally, terminology related to assisted dying is introduced.

MAiD as a Nursing Issue

Bill C-14 reads, "no social worker, psychologist, psychiatrist, therapist, medical practitioner, nurse practitioner or other healthcare professional commits an offence if they provide information to a person on the lawful provision of [MAiD]" (Parliament of Canada, 2016, p. 14). Nurses played a significant role in speaking into the legislation of MAiD, and they have continued to be involved directly and indirectly in the implementation of that legislation. For example, during the legalization process, multiple professional nursing groups submitted briefs and presented to the Committee their concerns within the Bill (Schiller, Pesut, Roussel, & Greig, 2019). The Canadian Nurses Association (CNA) argued for nursing involvement, and, in particular, that nurse practitioners (NPs) to be given the right to act as assessors and providers. The CNA's goal was to "recognize the importance of nurses and other members of the interprofessional healthcare team in MAiD. Nurses support patients and families during end-of-life care planning and act as vocal advocates for improved access to palliative care across Canada" (Schiller et al., 2019, p. 4). These concerns are now reflected in the new

language of *Medical Assistance in Dying*, which represents a clear recognition of the range of healthcare providers involved directly or indirectly with MAiD (Schiller et al., 2019).

Nurse researchers Pesut, Thorne, Greig, Fulton, Janke, and Vis-Dunbar (2019) explored the ethical, policy, and practice implications for nurses in relation to MAiD. These authors began by discussing a statement that was made by a physician at an international palliative conference. While describing his experiences with MAiD in Canada, the physician stated, "the most important predictor of how well a MAiD death will go is the presence of a nurse" (Pesut, Thorne, Greig, et al., 2019, p. 216). Pesut, Thorne, Greig, et al. went on to explain the various roles that registered nurses perform in the MAiD process. These included:

> (a) participating in assessment of competency and ability for self-administration; (b) providing information about MAiD; (c) coordinating the MAiD process; (d) preparing equipment and intravenous access; (e) coordinating and informing healthcare personnel; (f) documenting; (g) supporting patients and their significant others; and (h) providing postdeath care. (Pesut, Thorne, Greig, et al., 2019, p. 218)

Based on their synthesis, Pesut, Thorne, Greig, et al. (2019) noted that even when nurses were not directly involved with assisted death, "they provided wraparound care for patients, families, and other healthcare providers" (p. 221). Recognizing these important roles, it is clear that in the Canadian context, nurses are involved in significant ways with the assisted dying process.

In 2016, nurse ethicist Rodney (2016) called the Association of Registered Nurses of British Columbia (ARNBC; now Nurses and Nurse Practitioners of British Columbia NNPBC) into action, stating:

> RNs and NPs throughout B.C. must be engaged in the planning, implementation, and evaluation of MAiD in B.C.; evidence informed policies are needed to promote more equitable access to palliative care approaches; and professional development services related to fostering accessible palliative approaches to care are essential. (p. 2)

Rodney (2016) recommended that the ARNBC work closely with the CNA to "support equitable access to palliative care approaches in the context of [MAiD] through provincial educational and policy initiatives in British Columbia" (p. 1). As nursing colleges and associations across Canada have worked to do this, nurses at the bedside have continued to provide direct care for the terminally ill and the dying, as well as for their families.

MAiD in Canada

What is known regarding how MAiD is being implemented in Canada? The Canadian Institute for Health Information (CIHI; 2017) summarized discussion findings from a multiple-stakeholder meeting in a Discussion Forum Report. This report explicated the implementation of MAiD in Canada and emphasized that "there is a need for robust information about patient, family and provider experiences with MAiD" (p. 6). Acknowledging voiced concerns about inconsistent data reporting of MAiD and basic patient demographics of those requesting or receiving MAiD, the CIHI report underscored a serious need to establish a national minimum data set. As a result, various steps were taken to gather relevant data from MAiD assessors and providers across Canada, including the publication of regular reports from Health Canada.

Health Canada has tracked and collected data on the number of people who have opted for a medically-assisted death. For example, data from the *Fourth Interim Report on Medical Assistance in Dying in Canada* (Health Canada, 2019) indicated that the total

number of medically assisted deaths between December 10, 2015, and October 31, 2018 was 6,749. This number does not include those that took place in the territories (Yukon, Northwest Territories, and Nunavut), who could not share data due to small numbers and associated concerns related to protecting the privacy of patients and providers. This Health Canada data also excludes deaths that occurred in Quebec between April 1, 2018, and October 31, 2018, as reporting requirements were not yet standardized.

Of the participating jurisdictions across Canada who reported their collected demographic information, from January 1, 2018, to October 31, 2018, most cases of MAiD occurred in hospitals (44%) or at home (42%; Health Canada, 2019). A smaller number of cases occurred in a long-term care facility or nursing home (5%), hospice (4%), or other location (9%; Health Canada, 2019). The average age of persons receiving MAiD during this time was 72 years, though cases ranged from the age of 18 to 91+ (Health Canada, 2019). Of those receiving MAiD, 51% were men and 49% were women. Though data is not provided for all provinces or territories, from the most recent report, NPs provided 7% of medically assisted deaths, which indicates a 2% increase over the previous reporting period. NPs provided MAiD in British Columbia, Alberta, Ontario, and the Atlantic region. It is noteworthy that Quebec's legislation restricts the provision of MAiD to physicians. Overall, Health Canada notes that findings from this fourth report remain largely consistent with previous reports.

Ongoing reporting strategies have continued to be developed with federal *Regulations for the Monitoring of Medical Assistance in Dying* coming into force on November 1, 2018 (Health Canada, 2019). At this time, however, demographic data

related to the ethnicity, race, religion, or level of education of those receiving MAiD has not been collected. In these new regulations for monitoring, the practitioner must report:

> An indication of whether the patient received palliative care, if known, and (a) if the patient received palliative care, how long the patient received it, if known; or (b) if the patient did not receive palliative care, an indication of whether, to the best of the practitioner's knowledge or belief, palliative care was accessible to the patient. (Government of Canada, 2018)

As MAiD is still new in Canada, careful attention to demographic trends will prove vital in monitoring the processes surrounding MAiD and the social implications of this legislation.

Terminology Surrounding Assisted Dying

In summarizing and synthesizing the literature throughout this thesis, it should be noted that the studies included use various terms including euthanasia, physician-assisted suicide (PAS), family-assisted-suicide, physician-assisted death, hastened death, and assistance or aid in dying (AID). To reflect the included studies accurately, I employ the language and terminology used in each article. As Medical Assistance in Dying has been officially adopted in Canada, I use this term when speaking generally about the literature. In this section, I will explicate these terms more specifically.

To date, assisted dying is offered in some form in seven countries around the world (Pesut, Greig, et al., 2019). In the Netherlands, Belgium, Luxembourg, and Columbia, physicians may administer drugs to end a patient's life at his or her request. In Switzerland, physicians may prescribe or supply a lethal dose of medications with the explicit intention of enabling a person to end his or her own life. Residents of Oregon, California, Colorado, Montana, Vermont, Washington, and the District of Columbia in the United States may also make a request for physician-prescribed lethal doses of

medications for the purpose of self-administration (Rapid Response Service, 2017). Though each of these jurisdictions have legalized or decriminalized assisted dying, there are important distinctions between different forms of this assistance.

Defining MAiD. In Canada, persons who meet eligibility criteria can request MAiD from a physician or NP in two different forms: patients may choose to have the healthcare professional directly administer the substance which causes death (i.e., euthanasia); or, patients can choose to have the healthcare professional provide or prescribe a drug for patients to take by themselves, in order to bring about their own death (i.e., assisted suicide; Rapid Response Service, 2017). "[MAiD] is defined as care consisting in the provision, by a medical professional, of 'medications or substance to an end-of-life patient, at the patient's request, in order to relive their suffering by hastening death'" (Canadian Public Health Association, 2016, p. 1). According to the *Fourth Interim Report on MAiD in Canada* (Health Canada, 2019), from June 17, 2016, through Oct. 31, 2018, only six Canadians (excluding those from Quebec, Northwest Territories, Yukon, and Nunavut) chose to self-administer medications. This stands in stark contrast to the total 5,079 clinician-administered deaths in Canada during this time.

Defining assisted dying, euthanasia, and assisted suicide. In the Netherlands, Belgium, Luxembourg, and Columbia, *euthanasia* is legalized. It is defined as "the deliberate action undertaken by one person with the intention of ending the life of another person to relieve that person's suffering where that act is the cause of death" (Canadian Public Health Association, 2016, p. 1). Euthanasia is "the intentional termination of life by someone other than the person concerned at his or her request" (Dees et al., 2013, p. 28). In contrast, *assisted suicide*, as seen in Switzerland and the above-mentioned states,

"involves enabling the patient to obtain a lethal substance, which the person wishing to commit suicide then takes without any external assistance" (Gamondi, Pott, Forbes, & Payne, 2015, p. 146). In assisted suicide, "a person [may] intentionally help . . . another person to terminate his or her life at that person's voluntary and competent request" (Gamondi, Pott, Preston, & Payne, 2018, p. 1085). *Assisted dying* is a term that encompasses both euthanasia and assisted suicide (Gamondi et al., 2018). Wagner, Müller, and Maercker (2012) noted the importance of recognizing the critical differences between these terms and of taking their distinctiveness into consideration when comparing results in studies abroad.

Defining family. In addition to the terms described above, the term *family* used in this study requires definition. Various terms are used throughout the literature to describe familial relationships including relatives, family members, and loved ones. In some studies, *relatives* included in the sample are described as spouses, neighbours, friends, siblings, parents, and cousins (Snijdewind, van Tol, Onwuteaka-Philipsen, & Willems, 2014, p. 1128). In another study, *bereaved family and friends* were divided into partners, children, or siblings, and *others* which included cousins, friends, and in-laws (Wagner, Müller, et al., 2012, p. 545). Another study defined family member as "chosen families and close friends, as well as affinal kin" (Starks et al., 2007, p. 107). For the purposes of this study, family was defined broadly, "allowing each person to define who or what constitutes family" (Baumann, 2006, p. 15). Family relationships, therefore, were not limited to biological or legal ties (Baumann, 2006). In this study, individuals who identified as a family member of someone who received MAiD were included, regardless of their biological or legal connection to the patient.

Theoretical Perspectives Relevant to this Study

Since June 17, 2016, Canadians have been able to request and receive assisted dying, and though the long-term societal impact of this legislation has yet to be seen, the impact of MAiD on family members is an important consideration for policymakers, healthcare professionals, and the general public. The purpose of this study, therefore, was to examine how family members experience MAiD and to consider the associated implications for nursing practice. In order to do this, it was necessary to examine the contextual factors underlying how MAiD is carried out across Canada. The policies, procedures, and processes surrounding MAiD are located both within the biomedical model as well as within the palliative care philosophy, creating a noteworthy tension with implications for how family members may experience their loved one receiving MAiD. The theoretical perspectives inherent in each of these models will be discussed, with attention given to how these models may impact family members in relation to MAiD.

Overview of the Biomedical Model of Medicine

Recognizing the predominance of biomedicine, or modern medicine, in healthcare is key to understanding the context of MAiD in Canada. The point in the discussion that follows is not to argue that biomedicine is inappropriate to healthcare, but rather to uncover how its philosophical roots and everyday practice can inadvertently impact families' experiences of MAiD. According to public health researchers Naidoo and Wells (2016), the biomedical model "arose in Western Europe at the time of the Enlightenment, with the rise of rationality and science as forms of knowledge" (p. 7). They noted that prior to this, religion provided a way of knowing and understanding the world. This old order was substituted by science with the Enlightenment and Industrial Revolution. They

explained that "observation, calculation and classification became the means of increasing knowledge . . . In an atmosphere when everything was deemed knowable through the proper application of scientific method, the human body became a key object for the pursuit of scientific knowledge" (p. 7). With such a scientific-reductionist foundation, modern medicine is therefore predominantly based on objective measures (Hinshaw, 2013). This basis has implications for how patients, and subsequently, their family members, are viewed and treated within this model.

Naidoo and Wells (2016) critiqued biomedicine as mechanistic, conceptualizing the body as if it were a machine, with all parts being interconnected but capable of being separated, and therefore, being treated separately. They described biomedicine as allopathic, meaning treatment involves applying an opposite force to correct whatever is wrong with the body. In biomedicine, they noted, the term *health* indicates the absence of disease or illness, rather than the presence of what makes a person *healthy*. Naidoo and Wells described this model of care as dualistic, allowing the mind and body to be treated as separate entities. Scholars caution that in many ways, the scientific objectivity of biomedicine has shifted medical efforts away from caring for the person receiving healthcare toward treatment measures (Hinshaw, 2013).

According to palliative physician Hinshaw (2013), modern medicine has "focused on the cure of disease(s) as the real end or purpose of medicine . . . if modern physicians cannot cure or control a disease, this implies that they have failed, or worse yet, their patients have failed medical treatment" (pp. 21-22). Drawing on the work of psychiatrist George Engel in exploring this reductionist approach to medicine, Hinshaw emphasized, "Fundamentally, in Biomedicine if it can be seen, touched, defined, and better yet

measured, then something can be done about it. Psychological, emotional, and social issues are too soft, squishy, and ill-defined and thus are excluded" (p. 17). This overemphasis on cure impacts how treatment is provided.

Beyond influencing the provision of treatment, biomedicine also shifts responsibility away from the patient, placing it in the hands of physicians. It reduces the particular, or the individual person, to that which can be generalized (Frank, 2013). Describing the roots of modern medicine, Canadian sociologist Frank (2013) explained that this generalization "created a benevolent form of colonialism" (p. 11). This colonization was key to the achievement and predominance of this model in healthcare. As Frank noted, "medicine claimed the body of its patient as its territory, at least for the duration of the treatment" (p. 10).

Frank (2013) argued that, until recently, this colonization was deemed worth the attempted or achieved cure. Even today, in the biomedical model, ill persons are required to "delegate responsibility for their health to physicians; illness responsibility is reduced to patient compliance" (p. 15). Frank went on to say that "according to modernist universalism, the greatest to *all* patients is achieved when the professional places adherence to the profession before the particular demands of any individual patient" (p. 15). As patients have begun to grow tired of surrendering their responsibility and their own unique experience to medicine, there is a movement where individuals are trying to place themselves outside of the general view modern medicine has reduced them to. Out of this modern medicine comes what Frank describes as a transition to postmodernity and postcolonialism. With this transition, "ill people still surrender their bodies to medicine, but increasingly they try to hold onto their own stories" (p. 16).

Through examining the social context of MAiD in Canada, evidence of biomedicine can be seen in several noteworthy ways. In the following sections, I explain how biomedicine can result in a perpetuation of mind-body dualism and can lead to an intolerance and avoidance of suffering, as well as a resistance to meaning-making in times of suffering. It can also lead to the prioritization of autonomy and individualism as primary values within a society. In these ways, the outworking of biomedicine in Canadian healthcare presents important considerations for how family members may experience MAiD.

Mind-body dualism. As mentioned above, a biomedical model in healthcare results in a focus on objective, measurable, treatable, and curable outcomes. This focus has perpetuated a mind-body dualism that continues to shape much of today's medicine. Although quantifiable measures are essential for the diagnosis and treatment of disease, this approach has limitations. As Hinshaw (2013) summarized:

> By their nature, emotional, social, or spiritual experiences of the patient or caregiver are subjective and qualitative. Thus, in this model they are not "scientific" and therefore are basically suspect. Inevitably, the emphasis on the objective/scientific approach has shifted the focus of medical effort to disease as a target of treatment and away from the person. As a consequence, a mind-body disconnect has developed in Western modern medicine. (p. 16)

The well-known meditation of French philosopher Descartes (1637/2006) in the seventeenth century, proclaimed, "I am thinking therefore I exist" (p. 29), or more popularly translated as, "I think, therefore I am." Descartes considered the mind and body to be distinct, with the mind being superior to the body (Bordo, 1993). This separation of body and mind, and the privilege given to one's mind or one's cognitive ability, has prevailed in medicine. Alongside an over-emphasis on measurable outcomes, this separation of body and mind has resulted in the diminishing of value of any non-

biological aspects within an individual's experience. In biomedicine, that which can be observed and known takes precedence over that which is only felt or sensed. Challenging this relationship presented by Descartes, the work of French phenomenological philosopher Merleau-Ponty (1962/1982), emphasized instead the notion of the "lived body" (as cited in Piran & Teall, 2012, p. 170). Piran and Teall (2012) explained Merleau-Ponty's assertions that the consciousness actually resides in the body. For Merleau-Ponty, "the mind and body were equivalent, intertwined, and inseparable," and the body was "a subjective site that senses and experiences the world meaningfully" (Piran & Teall, 2012, p. 170). This understanding of the mind and body stands in stark contrast to the idea that the body is simply a physical object to be seen and touched by others (Piran & Teall, 2012).

Rooted in the writings of Merleau-Ponty (1962/1982), embodiment has become a construct referring to "a state of connection between the mind and the body" (Piran & Teall, 2012, p. 170). Though embodiment can represent a range of positive experiences including "embodied, agency, self-care, joy, attunement with the body, and functionality" (Piran & Teall, 2012, p. 172), it can also represent more negative experiences, or disruptions to an embodied life. Hinshaw (2013) argued that biomedicine's objective, measurable, and scientific approach has contributed to a disrupted embodiment in Western medicine.

Is there evidence of this mind-body dualism in current practices and procedures related to MAiD? Critics of biomedicine argue that an emphasis on cure, over care, has permeated the way healthcare providers, or perhaps more accurately, health *cure* providers, have delivered their treatments and healing efforts. In a sense, within this

model, MAiD could be seen as a treatment that is offered to *cure* death. Hinshaw (2013) cautioned, "When one attempts to cure disease without caring for the person (breaking up the psychosomatic unity), this attempt can cause suffering" (p. 49). Physician and clinical professor Cassell (2004) wrote, "The understanding of the place of the person in human illness requires a rejection of the historical dualism of mind and body" (p. 32). If care is going to be focused on the person, rather than the treatment, the dichotomies presented in biomedicine of mind and body, cure and care, must be acknowledged and addressed. I return to these dichotomies in my discussion of the findings from this study.

Intolerance for suffering and resistance to meaning-making. As mentioned earlier, some social scientists argue that biomedicine requires the patient give over their responsibility to the physician and remain compliant with prescribed treatments. The patient's illness narrative is surrendered to the system they are in. As Frank (2013) explained, "hospitals trade in endless bits of information. At best, this information coalesces into a coherent medical narrative of the disease. But this narrative is a *technical account* of the disease, its possible cause and expected progression" (p. 190). The patient's own subjective experience is often not heard. Frank argued that this handing over of their responsibility and their story to physicians has resulted in ill persons no longer having to search for meaning in their suffering. Instead, they become compliant recipients of cure, with their experience generalized to be that of other patients with similar diagnoses. This surrender of responsibility and story, along with the mind-body dualism described above, has led to an intolerance for human suffering of any kind. Without a sense of purpose, anything that threatens an individual's physical or cognitive ability must be avoided; any suffering or loss is deemed meaningless.

In contrast to how stories are held and heard in the modern medical model, Frank (2013) explained that postmodern illness stories are told with the goal of individuals placing themselves outside the general view modern medicine has reduced them to. With this movement in their stories, the ill patient is not simply responsible for getting well, rather, "the post-colonial ill person takes responsibility for what illness means in his life" (Frank, 2013, p. 13). Though this carries with it a potentially overwhelming burden, incentive to seek meaning and understanding in the midst of illness can lead to an acceptance of suffering.

In addition to the emphasis on mind-body dualism and the surrendering of a patient's responsibility and story (both characteristic of biomedicine), a narrow understanding of autonomy has also contributed to an intolerance for suffering at individual, collective, and societal levels. In his essay, *The Malaise of Modernity,* Taylor (2003) critiqued what he calls "the dark side of individualism" (p. 4). This individualism, which is praised and fought for in healthcare, also finds its roots in biomedicine. Taylor (2003) explained:

> We live in a world where people have a right to choose for themselves their own pattern of life, to decide in conscience what convictions to espouse, to determine the shape of their lives in a whole host of ways that their ancestors could not control. And these rights are generally defended by our legal systems. In principle, people are no longer sacrificed to the demands of supposedly sacred orders that transcend them. (p. 2)

He went on to explain that the modern freedom we now experience was won by breaking loose from older moral orders. Though these orders restricted us, they had significance given to them based on their place in the "chain of being" (Taylor, 2003, p. 3). Rituals and societal norms had "more than merely instrumental significance" (Taylor, 2003, p. 3). With this newfound modern freedom, Taylor (2003) explained that individuals have also

lost something important—that is, a sense of higher purpose. The consequence of this has been a narrowing—a loss of a broader vision beyond themselves. The resulting centering on the self "both flattens and narrows our lives, makes them poorer in meaning, and less concerned with others or society" (Taylor, 2003, p. 4). This narrowing has resulted in an elevation of autonomy. It is this narrowing that Taylor (2003) described as "the dark side of individualism" (p. 4).

A consequence of such individualism is a minimization, intolerance, and avoidance of suffering. Rusthoven (2014) summarized:

> Charles Taylor insightfully and rightly notes that minimizing suffering is an outworking of the modern notion of human autonomy. It is a consequence of the loss of belief that human beings play any role in a larger cosmic moral order and related divine history. Revulsion for suffering of any kind is a utilitarian response to a perception of human suffering as always needless. (p. 250)

As a western nation, propelled by individualistic ideals, and with a shift from a religious framing of death and dying to a nonreligious approach (Beaman & Steele, 2018), Canadian society is one that has become increasingly keen to diminish and avoid suffering, often in the name of protecting human dignity. Euthanasia and assisted suicide have become one of the most passionately debated topics in philosophy, bioethics, and medicine (Beaman & Steele, 2018; Frey & Hans, 2016). Pesut, Thorne, Greig, et al. (2019) anticipate an increase in the acceptance of assisted dying in Western jurisdictions. They explained,

> there are data to suggest that, culturally, we are thinking about death in new ways. Data collected from jurisdictions where assisted death is legal have indicated that most individuals seek assisted death for existential reasons rather than due to suffering of an entirely physical nature. The move toward assisted death is likely manifesting broad-scale cultural ideas about a good death and a good life. Sudden death has become the new ideal. (Pesut, Thorne, Greig, et al., 2019, p. 226)

In their discourse analysis of the *Carter v. Canada* (2015) case, Beaman and Steele (2018) noted that the Supreme Court of Canada's decision demonstrates a significant social shift away from transcendent and religious conceptualizations of suffering, pain, illness, and assisted dying, toward a nonreligious conceptualization. As the percentage of Canadians who identify as nonreligious has increased from 16.53 percent in 2001 (Statistics Canada, 2003), to approximately 23.78 percent in the most recent 2011 Canadian National Household Survey (Statistics Canada, 2013), Beaman and Steele (2018) argued that "the shift in tone in law is a reflection of a significant move away from a religious framing of death and dying to a nonreligious framing" (p. 130). They argued that in a religious approach to dying, illness and suffering can be viewed as good, "and any attempt to control the time and place of death is seen as being contrary to the sanctity of life which is ultimately attributable to that transcendent being" (p. 131). They suggested that a religious approach to dying, illness and suffering leaves little place for human agency. A nonreligious model of dying, they argued, "affirms individual agency and choice," thereby reframing sanctity of life as "including the ability to choose the time and place of one's death" (p. 131). A nonreligious approach to assisted dying is, as Beaman and Steele (2018) explained:

> a shift in terminology; dignity rather than suffering as the ultimate goal for human beings; an emphasis on individual agency instead of a transcendental being or notion of "gods will"; and a move from a moral assessment to medical assessment. (p. 134)

They concluded that as the discourse around suffering and dying shifts, the "view of death as God's will, or suffering as a moral good, has lost its privileged status and is becoming only one possibility amongst other alternatives" (p. 139). This shift in

discourse is consistent with biomedicine and has implications for healthcare providers caring for both religious and nonreligious patients.

Much of the justification for MAiD in Canada stems from a desire to honour the individual rights of the patient who wishes to end their unbearable suffering. In their systematic literature review exploring family members' experience of assisted dying, Gamondi, Fusi-Schmidhauser, Oriani, Payne, and Preston (2019) noted that, "In general, witnessing patient's suffering becoming unbearable over the illness experience represented for family members a key motivator to agree with their request for assisted dying" (p. 8). Along with the burden of witnessing profound suffering, Schiller et al. (2019) found that, in studying nurses' experiences with MAiD, some nurses resolved their own moral uncertainty about MAiD by appealing to its legality. Other nurses appealed to ethical reasoning, in "that their primary reason for engaging with MAiD was to support patient autonomy and choice, a primary good that shaped nurses' perceptions of their legal and ethical obligations" (Schiller et al., 2019, p. 2). Citing Deneen (2018), Schiller et al. (2019) explained that:

> the current modern liberal constitutionalism is based largely upon anthropological assumptions of individualism and choice. Liberty, defined as individual freedom of choice, then becomes the criterion by which we judge the goodness of society's law, policy and morality. (p. 2)

Although Schiller et al. (2019) noted that not all nurses in their study gave primacy to the values of choice and autonomy, this certainly was a primary reason why many nurses engaged with MAiD. Within a biomedical model, then, which places such high value on autonomy and individualism and such low value on suffering and meaning-making, how might healthcare providers best ensure that patients and their family members are still

given opportunity to reclaim their illness narrative and to seek meaning in their experience of suffering?

Autonomy and individualism. Closely connected to the value of individualism and avoidance of suffering, and a central principle in Canadian healthcare and biomedicine, is respect for autonomy (Beauchamp & Childress, 2001). Summarizing Sherwin (1998), Rodney, Burgess, Pauly, et al. (2013) explained that a conventional understanding of autonomy acknowledges that an autonomous individual has the opportunity to: "(1) be 'sufficiently competent' to make a decision; (2) choose reasonably from the available options; (3) obtain adequate information and demonstrate understanding of the information related to the options available; and (4) not be coerced by others" (p. 93). Describing autonomy in the context of bioethics, and also opening the door to a critical appraisal of these interpretations of autonomy, Moyse (2015) wrote:

> Respect for patient autonomy continues as an often-praised achievement of contemporary biomedical ethics, which tends to guide any decisions. Addressing the primacy and import of one's wishes, rather free choices, over against those that might be imposed by others is vital for much decision-making in clinical and laboratory settings. Accordingly, autonomy is often regarded as an individuals' capacity for self-determination or self-governance without impediment or discernible harm to others. However, despite this description, the concept of autonomy remains a much-contested one and the various philosophical distinctions tend to be blurred. (p. 98)

As Moyse (2015) noted, there are various definitions and understandings of autonomy. Despite these varying interpretations, the principle carries significant weight in how healthcare is provided in Canada.

In issues related to assisted dying, the principle of respect for autonomy often emphasizes the individual. Snijdewind et al. (2014) explained:

> The notion of autonomy that is now present in the euthanasia debate is closely linked to the strict individual autonomy of the patient. Yet, in practice, a more

> relational form of autonomy seems to be at work. The performance of euthanasia often is the result of a decision shared by the patient, the physician, and the relatives involved. Perhaps we should think about a notion of autonomy that is more shared and equal. (p. 1132)

In a similar vein, also in relation to MAiD, Canadian nurse researcher Reimer-Kirkham (2017) asked the questions: "Are there limits to autonomy and self-determination? How do we balance the rights of an individual in the context of community and relational ethics?" (para. 5). In regards to health inequities, Canadian nurse researchers Varcoe, Browne, and Cender (2014) encouraged us to scrutinize the social processes and structural injustices which perpetuate these, including the biomedical and individual discourses which promote individual autonomy, individual rights, and self-determination over the broader rights of society as a whole.

In their background paper, Kouwenhoven, van Thiel, van der Heide, Rietjens, and van Delden (2019) observed that:

> the approach to euthanasia as a practice based on the physician's conflict of duties [to alleviate unbearable suffering and at the same time preserve the patient's life] is shifting towards euthanasia as a practice grounded in the patient's autonomous choice. (p. 44)

They explained that the numbers of cases of euthanasia in the Netherlands have increased from 1.7% of deaths in 2005 to 4.5% in 2015, with 80% of cases now reporting the main reason for euthanasia as the patient's wish or no prospect of improvement. With this percentage higher than that of pain or other symptoms, Kouwenhoven et al. wondered if "this could point [to] an increasing demand of patients to control their end-of-life" (p. 44). They cite a public initiative which occurred in 2010 "with the aim to legalize assistance in dying for elderly people who consider their life completed" (p. 45), as an example of the movement underway to declare patient autonomy "as a right" (p. 47).

Kouwenhoven et al. concluded that "these developments show a change in society in the direction of more self-empowerment and even towards a right to die" (p. 44).

To make sense of this shift, Kouwenhoven et al. (2019) differentiated between *negative* autonomy, or the dimension of autonomy that is understood as a "right to freedom and self-determination" or "freedom from external interference in one's own life," (p. 46) and *positive* autonomy, which frames autonomy as an ideal, with the autonomous self being viewed as a process, recognizing humans as social creatures who interact with one another. In negative autonomy, the physician's role could be viewed strictly as instrumental, meaning that a doctor should grant an euthanasia request whenever possible. Kouwenhoven et al. noted, however, that a positive perspective of autonomy allows for a shared decision-making model which can create space for trust to form between the practitioner, the patient, and involved relatives, all resulting in fewer complexities. Kouwenhoven et al. concluded that patients who request euthanasia may benefit from "an approach of autonomy 'as an idea' versus the approach of autonomy 'as a right'" (p. 47).

Snijdewind et al. (2014) also suggested that a shared view of autonomy may be beneficial in integrating family members into the process of assisted dying. Differentiating between the process of euthanasia and physician-assisted suicide (EAS) and the event of EAS, Snijdewind et al. (2014) asked:

> If the process toward EAS is so important, one may wonder who should be involved in this process: is it ethically justifiable for a physician and or perhaps even the patient to leave close relatives out of this process, when we have seen that relatives play such an important role? (p. 1132)

Considering the logistics of such a perspective, they proposed that a more shared and equal view of autonomy might result in the role of relatives being made more explicit,

allowing for more active involvement in the process of EAS. Careful attunement to how biomedicine and its approach to autonomy has and continues to influence the legislation and implementation of MAiD in Canada will be necessary in attempting to understand the experience of family members whose loved one has received MAiD.

Overview of the Palliative Care Philosophy

Though MAiD is situated in the current healthcare context, which still favors the biomedical model, it is also most often placed under the umbrella of palliative care. How does this philosophy differ from the biomedical philosophy of care? In response to biomedicine, Engel (1977) proposed a bio-psycho-social model for healthcare that would acknowledge and embrace the wider factors impacting health and illness (as cited in Hinshaw, 2013). This model developed into palliative medicine (Hinshaw, 2013). In contrast to the previously described biomedical model, caring within a palliative care philosophy has a different emphasis. In palliative care:

> The focus is on a person and the relief of that person's suffering, including control of symptoms, and whenever possible, restoration of function. Caring does not depend so much on complete medical knowledge, but more on a relationship. Caring takes time and often is at odds with the demands for efficiency and rapid patient turnover of the acute care setting. Fundamentally, at the heart of caring for the sick is the relief of suffering. (Hinshaw, 2013, pp. 43–44)

As a philosophy, palliative care strives to relieve suffering, affirm dying as a normal process by neither hastening nor postponing death, and integrate psychological and spiritual aspects of care. Using a team approach, it supports patients to live as actively as possible, while supporting family members in their coping during and after the patient's illness and death (World Health Organization [WHO], 2019). Palliative care, as defined by WHO (2019), is:

> an approach that improves the quality of life of patients and their families facing the problem associated with life-threating illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (para. 1)

Not limited to the actual time of death, a palliative approach offers "care, treatment and support during earlier phases of severe illness, at end of life, as well as during bereavement" (Öhlén et al., 2017).

In their literature review and thematic analysis testing the content validity of the proposed conceptual model of a palliative approach, Touzel and Shadd (2018) drew upon 19 definitions of palliative care, which they then divided into four distinct conceptual categories: morality acknowledgment, focus on quality of life, whole-person care, and "other." They found that indeed, these domains reflect ideas in palliative care and that "a palliative approach exists when care simultaneously addresses whole-person needs, enhances quality of life, and acknowledges mortality" (Touzel & Shadd, 2018, p. 1634). Touzel and Shadd defined *whole-person care* as "care extending beyond the physical domain, addressing the psychosocial, spiritual and emotional domains of health. It involves understanding and supporting patients' values and beliefs, and treating one's patient and their suffering 'holistically'" (p. 1628). This stands in stark contrast to the mind-body dualism evident in biomedicine. Whereas the biomedical model of care emphasizes the treatable and the curable, palliative care attempts to underscore the various domains that impact a person (Hinshaw, 2013).

Van Den Boom (1995) stressed that, for many people, quality of death matters as much as quality of life. He emphasized:

> euthanasia is not the only way to improve the quality of death and dying. Equally important are the availability of palliative care, pain relief, anticipatory grief

> counselling and patient support. They stand alongside, and the one cannot replace the other. (p. S183)

It is with the aim of alleviating unbearable suffering that MAiD in large part exists. MAiD legislation in Canada requires that patients considering MAiD be offered palliative care (Pesut, Thorne, Stager, et al., 2019). However:

> the issue of whether MAiD should be considered as just one more end-of-life option within palliative care or whether it is antithetical to the palliative philosophy of neither hastening nor postponing death has characterized some of the debate about the relationship of MAiD to palliative care in Canada. (Pesut, Thorne, Stager, et al., 2019, p. 125)

MAiD is situated in tension within a biomedical model, which emphasizes a mind-body dualism, avoidance of suffering, individualism, and autonomy, and a palliative care philosophy, which strives to provide holistic care extending beyond the physical to enhance quality of life. By acknowledging this tension, we can better understand the factors influencing how MAiD is provided in Canada and, by extension, how family members experience the policies and procedures surrounding MAiD.

What does feminist theory offer?

With an acknowledgment of the tensions in which MAiD is situated, this study was designed to hear the complex experience of family members whose loved has received MAID. Feminist theorists have warned that "rational, non-contextual application of ethical principles misses the subtle and pervasive power dynamics that infuse patient/family/provider relationships within hierarchical institutions" (Rodney, Burgess, Phillips, McPherson, & Brown, 2013, p. 73). Rusthoven (2014) echoed this concern, noting that "autonomy as pure individual will and choice, outside of any relational context, is a false autonomy that is wrongly directed" (p. 250). It was with the goal of recognizing the broader context in which MAiD occurs that this study used Gilligan,

Spencer, Weinberg, and Bertsch's (2003) method of the *Listening Guide* (LG). Grounded in a feminist tradition, the method recognizes the collectivity of various voices within any person, noting the tensions among these voices "in culture, and in relationship with oneself and with others" (Gilligan et al., 2003, p. 157).

It is important to emphasize that hearing and valuing the experience of family members whose loved one has received MAiD does not necessitate the sacrifice of a patient's autonomy. Tilden and Lee (1997) stated, "an individual autonomy framework, rather than a family framework, has prevailed in the national debate about physician-assisted suicide for the terminally ill. However, the separation of individual and family is artificial in the context of life-threatening illness" (p. 120). Frey and Hans (2016) positioned assisted suicide within a family systems theory. They explained, "the decision to end one's own life profoundly impacts the family network within which the individual is embedded" (p. 251). Individuals must recognize that their actions impact others, including family members (Frey & Hans, 2016).

In reflecting on the highly controversial topic of assistance in death, van den Boom (1995) drew attention to the importance of building awareness. In the discussion surrounding MAiD, he noted that decision-making is complex, as it is held up against a background of ethical, moral, religious, and legal opinions. He wrote:

> Advocates of euthanasia base their views on the right to self-determination of the individual. Opponents claim that euthanasia would be in conflict with the right to life. Unfortunately, in many occasions there is no exchange of information and too little motivation to gain insight into each other's viewpoint. (p. S182)

This study sought to gain insight into these differing viewpoints.

In light of person-centred care, which aims to approach "the patient as a person; a human being with biography" (Öhlén et al., 2017, p. 2), we must be careful not to remove

the person from their broader context. Öhlén et al. (2017) noted a problematic tendency to "affiliate person-centred care with an individualistic or micro level focus. The person is always socially and societally contextualized" (p. 7). This tendency to focus on the individual in person-centred care is revealed in a reflection of Coombs, Lee, and Grube (2017), who stated:

> The tenets of patient autonomy and social justice have risen to become paramount ideals in the doctor-patient relationship, and a movement toward "patient-centered" or "person-centered" care has emerged . . . the common concept is the patient's preferences needs, and values that guide clinical decisions. (p. 39)

Coombs, Lee, and Grube (2017) went on to say:

> If healthcare systems truly want to deliver on their commitment to be "person-centered," then they must implement policies that respect the values of their consumers, including a patient's control over the circumstances of their looming death. In other words, adopting policies that support giving terminally ill patients the option of medical aid in dying is a hallmark of person-centered care. (p. 40)

While person-centred care does certainly acknowledge the person receiving care, it must also acknowledge the social environment surrounding that patient. MAiD does not happen in isolation, but in a relational context. In order to take an ethical stance toward person-centred care (Öhlén et al., 2017), we must consider family perspectives related to MAiD.

Post-structural theorists have disputed conventional views of autonomy suggesting that "the very idea of autonomy is a sort of illusion of the Enlightenment conception of person" (Rodney, Burgess, Pauly, et al., 2013, p. 93). A more relationally composed understanding of autonomy insists that understandings of self, identity, and autonomy are "products of language and power" (Rodney, Burgess, Pauly, et al., 2013, p. 94). Post-structuralist and feminist theorists encourage us, therefore, to consider the power dynamics within the sociopolitical contexts we operate in and to "consider the

complex network of relationships that the persons we serve—and we ourselves—are embedded in" (Rodney, Burgess, Pauly, et al., 2013, p. 94). Parks (2000) argued that the focus on self-determination, individualism, and autonomy in the euthanasia debate has removed the patient from their context. She explained:

> But feminist ethicists argue that practices like active euthanasia and physician-assisted suicide are not merely cases of individualized decision making: such individual decisions are made within a social context that informs and affects individuals' choices. Thus unlike liberal accounts of the self, feminist approaches view the individual as a socially embedded, interdependent relational subject whose choices are made within a complex web of social relationships. Where the euthanasia debated is concerned, the situated subject is not an isolatable, independent, atomistic subject: her choice to die has implications for both self and society, and her choices can be either upheld or undermined by the prevailing social ethos. (Parks, 2000, p. 32)

It is with the aim of considering this complex network of relationships that this study utilized a qualitative research methodology rooted in a feminist tradition.

Dees et al. (2013) highlighted the value of researching in a way that encourages "learning in reflection" (p. 35), providing opportunity for those involved in assisted dying to reflect on the process as a whole. A feminist qualitative design has created opportunity for this "learning in reflection," as "[p]articipants in narrative and/or feminist qualitative studies are often encouraged to be active agents, exploring subjective meanings and experiences that have been ignored or silenced in previous research, allowing for new insights and awareness into social processes" (Fraser & MacDougall, 2017, p. 243). Specifically, the LG, a Voice Centered Relational Approach, was used to guide analysis. This method assumes that each person has multiple simultaneous voices re-occurring within our psyche. These voices may be in tension with one another, with the self, with the voices of others in relationship, and with the culture or context in which the individual lives (Gilligan et al., 2003). By seeking to hear the voices of family members

whose loved one has received MAiD, and by acknowledging the larger social processes at play surrounding the implementation of MAiD in Canada, this study has aspired to honour the complexity and variation of human experience.

Thesis Description

Thesis Purpose and Objectives

This thesis aimed to hear and understand the experience of family members whose loved one has received MAiD. As the implementation of MAiD in Canada is still in its early years, conducting a study which explicitly seeks to hear how the legislation and the carrying out of subsequent policies has directly and indirectly impacted family members was a necessary step to ensuring that the complexities surrounding assisted dying are acknowledged. This study did not examine how MAiD impacts the family as a unit, nor did it examine how family members perceive the patient's experience of MAiD. This study also did not examine the experience of those whose loved one requested MAiD, but did not receive it, either due to not meeting the eligibility criteria or due to other factors, including loss of competency or death prior to the completion of the assessment process. The objectives of the study were to ask:

1. How do family members describe being involved with MAiD?
2. How are family members' values and beliefs acknowledged or integrated into the process or experience of MAiD?
3. How do individuals find or make meaning in their loss of a family member who received MAiD and how does this evolve over time?
4. What insights do family members have for healthcare providers involved in MAiD, and what are the implications for nurses?

By hearing the voices of family members, nurses can reflect on how these unique experiences might direct future practices and policies related to MAiD.

Thesis Method

As mentioned above, this qualitative study, grounded in a feminist tradition, focused on the lived experience of family members whose loved one had received MAiD. I conducted semi-structured interviews lasting approximately one hour with seven participants from across Canada. Recruitment strategies included purposive sampling, as well as connecting with agencies who provide support to patients or family members with respect to MAiD, including Dying with Dignity Canada and multiple hospice agencies. In this way, effort was made to hear from a breadth of perspectives, maintaining the overall aim of hearing various ways in which family members experience MAiD. The LG was used for analysis, allowing for the complex experiences of family members to be heard.

Relevance and Significance

Since June 2016, MAiD has been available to Canadians who meet the eligibility criteria. As this new legislation is implemented across the country, healthcare professionals and policymakers must consider how MAiD impacts individuals, families, and society in general. Family members are often involved in some way with the process and experience of MAiD, and they are thereby impacted by this unique end-of-life experience. Hearing how family members experience MAiD, therefore, is vital in informing future decisions and practices surrounding MAiD.

Outline of Thesis

Having situated MAiD in the Canadian healthcare context, this thesis further examines how this context impacts the experience of family members. In Chapter Two, I

provide a detailed and critical review of the existing literature related to how family members experience MAiD. The review identifies themes in the literature, as well as gaps, providing rationale for this particular study. In Chapter Three, I describe the methods used for data collection and analysis, followed by findings in Chapter Four. I then discuss these findings in Chapter Five, in light of the literature. In Chapter Six, I present conclusions from the study and recommendations for nursing and other healthcare providers. I deliberately do not include a stance pro or contra MAiD. Rather, my intent is to inform those involved in this field, including members of the interdisciplinary team, researchers, and family members themselves, of the experiences of my participants.

Chapter Summary

The impact of MAiD on family members in Canada remains largely unknown. This study aspired to honour the unique and complex experience of family members whose loved one has received MAiD. In order to do this, healthcare providers and policy makers must first acknowledge the contextual factors influencing how MAiD is carried out in Canada. Given the recent change in legislation allowing for assisted dying, healthcare providers and policy makers have a unique opportunity to speak into the implementation of processes and procedures surrounding MAiD. By seeking to hear and understand how family members experience MAiD, this study encourages nurses to reflect on these perspectives and to consider how they might influence future nursing practice and health policy.

CHAPTER TWO: LITERATURE REVIEW

In order to understand how family members experience MAiD, a systematic literature review was completed. I begin this chapter with a description of the search strategy that was utilized, including the criteria used to select relevant articles. Drawing on this synthesis, I summarize the current evidence on how family members describe being involved with MAiD, as well as how the values and beliefs of family members are acknowledged or integrated into the process of MAiD. How individual family members find or make meaning over time will be considered, along with insights from family members for healthcare providers involved with MAiD. From these articles, I describe how MAiD may present family members with both opportunities and burdens in their own bereavement process. Finally, I identify gaps in the current literature, thereby providing rationale for this study.

Searching the Literature

The literature search was an iterative process spanning several months. Initially, I identified key search terms through searches using Google Scholar and the university library. Upon consultation with a university librarian and my thesis supervisor, I identified three key searchable concepts to include: (i) terms for various family members or relatives, (ii) terms related to experience and meaning, and (iii) terms relating to assistance in death. Various key terms related to these three concepts were identified by reviewing MESH terms and related articles (see Appendix A). I utilized four library databases in order to ensure that disciplines outside of nursing with relevant related research were represented in the literature: (a) CINAHL complete, (b) PsychINFO, (c) MEDLINE full-text, and (d) ATLA. A total of $n = 545$ articles were identified using these

databases. I removed duplicates manually and by using Endnote. Next, I screened articles first by titles, followed by titles and abstracts using initial inclusion and exclusion criteria. I then assessed these articles for eligibility using final inclusion and exclusion criteria (see Appendix B). Backwards reference searching or an *ancestry approach* (Polit & Beck, 2012) was used to ensure that no relevant articles were missed. By using citations from relevant studies to track down earlier research on the same topic, I added additional articles for a total of $n = 11$ articles. The selection process is portrayed in a PRISMA chart (see Appendix C).

These 11 selected articles spanned the years from 1994 through early 2018, and they reported research conducted in the Netherlands, Switzerland, and both Oregon and Washington state. Four of the studies used quantitative research designs, attempting to measure aspects of grief in bereaved family members whose loved one has received assisted dying in some form. Sample sizes ranged from $n = 85$ to $n = 505$ bereaved family members. Six of the studies were qualitative in nature, exploring how family members are involved in the process and experience of assisted death, how they experience the decision-making phase of assisted dying, and how assisted death impacts their grief. Sample sizes range from $n = 7$ to $n = 35$ family members. One early study used a mixed-method design with both a questionnaire and face-to-face interview to understand the relationship between AIDS, euthanasia, and grief.

Given the length of duration of this project and to ensure comprehensiveness and inclusion of any new research, I re-ran my literature search in early 2020, near the completion of this thesis, on the four above mentioned databases, using the same limiters and search terms. After screening, five additional articles with relevance to this study

were added, for a final $n = 16$. Of these articles, published in 2018 and 2019, one utilized a mixed-methods study design, and four used a qualitative methodology. Each of these studies explored the experience of family caregivers, family members, or close friends whose loved one received assisted dying.

Though careful steps were taken to develop a comprehensive, systematic, reproducible, and non-biased literature review (Polit & Beck, 2012), several considerations are important to note. First, my key search terms related to family imply a traditional understanding of who might be considered by the patient to be *family*. To mitigate this, and to ensure a realistic number of initial articles to apply inclusion and exclusion criteria to, I updated search terms to include additional terms for less traditional familial relationships such as partner and relative. Second, it is important to note that no distinction was made between family member and family caregiver in the literature search. This was done intentionally, so as to retain a comprehensive yield of articles. I recorded a memo, however, to ensure that this distinction was examined as a potential point of interest in my own study. Third, as this search has included studies from around the globe and has been informed by practices and perspectives from other countries that have legalized assisted dying in some form, there is a possibility that some relevant findings have been missed due to a language barrier. This has been mitigated by reading summarized versions of these studies' findings in English articles. Through systematically searching the literature, abstracting the articles for relevant findings related to my research questions, and synthesizing both the major themes and gaps in the literature, I have begun to take ownership of this literature itself (Garrard, 2014). This

process guided me in the development of my own study to understand how family members experience MAiD in Canada.

Synthesizing the Literature

After identifying 11 key articles, I drew on Garrard's (2014) review matrix method to develop extraction questions as part of an iterative process. These questions were then applied to each article, in an attempt to systematically identify patterns and themes related to how family members experience MAiD. Extraction questions included the following:

1. Who is considered to be a family member or relative? What is the nature of the relationship?
2. How did the opportunity to say "goodbye" impact the family member(s)?
3. Were family members present at the time of death? How did this impact their experience?
4. Does the article comment on grief, including concepts such as complicated grief and anticipatory grief?
5. Were family members part of the decision-making process to receive assisted death? How did this impact their experience?
6. Did family members feel that they could be transparent with their experience? Did they experience any negative effects of stigma? Was MAiD considered taboo? Did they have to keep their experience a secret? Were they able to talk about their experience with others?
7. What aftercare or bereavement supports were provided or offered to family members?

8. How do family members speak of the patients' suffering prior to receiving assistance in death?
9. How do family members speak of honouring the patients' autonomy or decision? Did honouring the patients' wishes provide peace to family members?
10. How did the meaning-making process evolve over time for family members?
11. Was their conflict or disagreement amongst relatives or between family members and the patient related to assisted dying?
12. Does the fact that the quality of death is predictable and predetermined impact the family members' experience?
13. Which healthcare professionals are mentioned in regards to assisted death?

After considering these extraction questions, I noted each study's findings, strengths, limitations, and recommendations. A list of key terms and definitions in the literature was also created. By analyzing each article, I was able to evaluate what the literature says regarding this thesis' research questions. In the remainder of the chapter, I summarize the existing evidence relevant to my study.

Family Members' Experience of MAiD in the Literature

As a social process, dying engages ill persons, along with their families, friends, and healthcare professionals, in various tasks (Starks et al., 2007). Starks et al. (2007) stated that "families are the primary source of caregiving and support through serious illness and the dying process" (p. 125). To date, most research related to assisted dying has focused on the ethics surrounding the controversial matter (Snijdewind et al., 2014)

or on legal implications of intentionally ending a person's life (Wagner, Müller, et al., 2012). Gamondi et al. (2015) explained:

> Much of the national and international debate on assisted suicide is focused on ethical rights and duties, very often viewed from opposing positions, leading to a polarized debate. Far too little attention has been paid to the bereavement experiences following from a hastened death. (p. 146)

Research that does include the perspective of relatives in relation to assisted death often focuses on the families' perception of the patient's experience or on the relationship between the physician and the patient (Snijdewind et al., 2014). As Starks et al. (2007) summarized, "little attention has been paid to the role of family members in planning and implementing a hastened death, despite the fact that they must live with the legal, moral, psychological, and social consequences of their participation" (p. 107). Ganzini, Goy, Dobscha, and Prigerson (2009) echoed this saying, "little attention . . . has been paid to the impact of physician-assisted death on family members" (p. 808). Wagner, Müller, et al. (2012) added that little research has examined the psychological impact on family members or friends of witnessing assisted suicide. In their synthesized literature review, Gamondi et al. (2019) argued that "ethicists, legislators and researchers' focus is predominantly on patients and refers less to family members. For example, families are only marginally considered in clinical guidelines and recommendations internationally" (p. 2). All of this points to a need for increased representation of family members in the research surrounding assisted dying.

In their literature review investigating the experience of MAiD from the family caregiver perspective, Goldberg, Nissim, An, and Hales (2019) sought to explore family members' beliefs and opinions about MAiD, how the process of MAiD impacts family members, how the intervention shapes their view of the quality of death of their loved

one, and the psychosocial outcomes experienced after their loved one's death. Goldberg et al. (2019) noted that much of the research literature to date has excluded informal caregivers from the discussion, focusing instead on the patient and healthcare-provider perspective of the MAiD experience. They noted:

> This is consistent with the patient-centered approach that is engrained as a standard of Western healthcare and the principle of individual autonomy which is often called upon to support the ethics of assisted dying. Given that family is so integral to the advanced disease experience, it is important to gain insight into how MAiD affects family caregivers in order to provide the best possible care not just to the patient, but to the family as a whole. (Goldberg et al., 2019, p. 3)

Recognizing the lack of attention to family members' experience of assisted dying in the literature, Gamondi et al. (2019) noted an exception in the Netherlands. There, the Dutch Medical Association clarified that "family members' opinions are not decisive in principle; however, it is advisable that the physician should consider the possible dissent of family members' and try to reconcile it as much as possible" (Gamondi et al., 2019, p. 2). In their systematic mixed studies review, Roest, Trappenburg, and Leget (2019) explained that the Dutch euthanasia law does not consider the position of family members, except that it requires EAS requests to be "free of undue pressure" (p. 2). They went on to say, "Dutch clinical guidelines on EAS also barely describe the position and relevance of family members in EAS decision-making. Hence, empirical findings on the involvement of family members in the practice of EAS raise practical and ethical questions" (Roest et al., 2019, p. 2). Despite this omission from the law, Roest et al. noted that recent qualitative studies do describe the involvement of family members in the decision-making process and note that "some physicians take family members' well-being and bereavement into account when deciding whether or not to grant a request" (p. 2). They also note that compared to their counterparts in other European countries, Dutch

physicians are found to speak most frequently with family members about end-of-life decisions (Roest et al., 2019). Though this attention to family member perspectives in the Netherlands is promising, the literature overall has not adequately explored the unique experience of family members in relation to assisted dying.

Involvement of Family Members with MAiD

Family members describe various types of involvement in assisted dying. In their qualitative study of 35 families conducted from 1997 through 2000 in Washington and Oregon, Starks et al. (2007) highlighted different tasks that family members are called upon to help with when their relative has requested assisted dying. In addition to the tasks often required when caring for the dying, such as illness and symptom management and participating in everyday life activities, life history review and closure work, Starks et al. (2007) summarized that family members may also be asked to acquire "how to" information about requesting assistance, learn which medications are required and how to save and store medications, and determine how to avoid a legal investigation in places where hastened death is illegal. The family member's role may involve acting as an advocate for their loved one, managing the environment by securing death certificates, and preparing back-up plans in the event of complications. In many cases, family members are present at the time the patient receives or takes the medication, and depending on where the assisted death happens takes place, family members may even be asked to administer the medications to the patient. Depending on the individual case, family members may then remain with the patient until the time of death. In cases of assisted death, family members may help organize the death itself and provide emotional support to the patient in ways such as a listening, companionship, and counselling.

In their recent study exploring caregivers' experiences with aid in dying in Vermont, Buchbinder, Ojo, Knio, and Brassfield (2018) conducted semi structured in-depth interviews with 19 caregivers, including family members, close friends, and others, who had been closely involved with the care of 11 terminally ill patients who pursued AID. In their study, they found that the social support provided by caregivers on the day of an AID death could be categorized as either emotional support, which including expressions of empathy, care, and love through shared presence with the patient, or as instrumental support, which entailed practical assistance in organizing what was needed to facilitate the patient's final wishes. These two forms of support were then distributed between four distinct temporal phases of preparation, ingestion, waiting, and after death. As compared with Canada, this study points to the added difficulty faced by patients pursuing AID in the United States. As per Act 39, patients in the United States are legally required to self-administer their medication. This step appears to add unique challenges to caregivers. For example, caregivers felt added anxiety as a result of not knowing how long the ingested medication would take to affect the patient. Caregivers also felt they had to provide emotional support for other family members and caregivers. Buchbinder et al. (2018) reported, "Several caregivers reported sublimating their own physical and emotional needs until after their loved one's death, expressing a desire to be strong for their loved one" (p. 939).

While facing the challenge of supporting their loved one's wish, family members must also consider their own moral values and emotional needs. Starks et al. (2007) described the involvement of family members as "midwifing the death" (p. 124), meaning that the family's or individual's role shifts from witness to facilitator. In all of

this, family members often have little preparation for their role. For some family members, their role includes protecting the memory of their loved one after receiving assistance in death. This may involve concealing specific details about the death to "spar[e] the stigma of suicide" (Starks et al., 2007, p. 125).

In their study on mental health outcomes of family members of Oregonians who requested Physician Aid in Dying, Ganzini et al. (2009) explored how patients' end-of-life choices affected family caregivers by measuring severity of grief symptoms, use of mental health services, and depression. A secondary goal of their study was to compare these outcomes with family members whose loved one had not pursued hastened death. A total of 95 family members whose loved one requested aid-in-dying were compared with 63 family members whose loved one had never requested hastened death. Of the 95 family members whose loved one requested aid-in-dying, Ganzini et al. (2009) compared the 59 family members whose loved one received a lethal prescription and the 32 who died after lethal ingestion. They found that of the family members (n = 36) whose loved one had died by ingestion, over 90% "felt at peace with and included in the decedents' end-of-life choices, accepted the death, and were satisfied with the opportunities to say goodbye" (p. 811). One in four either wished for more opportunities to care for their loved one or found it difficult to talk about the death, while 11% had regrets about how the loved one had died. Though numbers are not provided, Ganzini et al. (2009) noted that family members of loved ones who requested but did not receive a lethal prescription were more likely to "endorse that they had regrets about how the loved one died" (p. 811).

From their findings, Ganzini et al. (2009) stated that most often family members of patients who request assisted suicide support the patient's choice. They noted that although the law in Oregon requires a patient to "self-administer" the lethal medication, family members are very often present, and their assistance in the death may range from organizing appointments with the physician, obtaining and preparing the medications, and potentially even helping the patient take the medication. In the first year after death, no difference was found between aid-in-dying family members and comparison family members in prolonged grief diagnosis or symptom severity, in requests or access to mental health services after the death, in perceived levels of diminished social support, or in depression scores. Ganzini et al. (2009) concluded that "both action and inaction may have the risk of complicating grief and leaving the loved one with regrets" (p. 813). They suggested that family members who feel more prepared for death do experience a lower incidence of complicated grief (Ganzini et al., 2009).

In their qualitative study Dees et al. (2013) explored the relational dynamics between patient, physician, and relative in regards to the decision-making process surrounding the request for euthanasia in the Netherlands. Dees et al. (2013) examined 32 cases, which resulted in a total of 90 interviews with 31 patients, 31 relatives, and 28 treating physicians. They noted that while relatives were not in a position to determine the final decision about euthanasia, their lack of support did impede decision-making, while their support and respect resulted in positive outcomes. Relatives experienced the negotiation of date and time to be unnatural, and they preferred to not be involved in this aspect of the decision-making process. When it came time for the actual EAS procedure, the roles of family members shifted, and the rituals accompanying the event became

valuable to relatives, as well as to patients and physicians. Relatives noted that the rapid process of decision-making made their experience more challenging, and they commented that the process was burdensome for them. Dees et al. (2013) concluded that talking about the request for euthanasia was important in preparing family members for a loved one's death, and it helped facilitate "saying farewell" (p. 35). They also found that relatives had unresolved feelings about the speed of decision-making, the unnaturalness of the procedure, and that aftercare was not systematically provided.

Snijdewind et al. (2014) noted that although relatives do not have a formal, explicit role in euthanasia and physician-assisted suicide (EAS) in the Netherlands, "they are often present at important moments in the process of (requests for) EAS" (pp. 1127-1128). In their qualitative study, Snijdewind et al. (2014) examined both the relational complexities and the complexities that occur in EAS as a result of unexpected situations occurring. To do so, they conducted in-depth interviews with 28 Dutch physicians and 26 relatives of patients who had died by EAS. While their interview findings discuss the important relationship which forms between the physician and the patient in the process toward EAS, it is noted by Snijdewind et al. (2014) that family members also played an important part in this relational process. Family members who had not been a part of this process experienced more complicated grief. When discussing the complex situations surrounding EAS, Snijdewind et al.'s (2014) findings demonstrate that the process toward EAS is more important than the event of EAS, and it requires time and the building of relationships. Their findings indicate that the process of EAS should "be seen as a triangle among physician, patient, and relatives" and that relatives should not be overlooked (p. 1131). This statement confirms the findings of Starks et al. (2007), who

also noted that family members who had did not fully participate in the planning process felt unprepared to deal with the complications they encountered.

There remains great diversity in how family members are involved in assisted suicide (Gamondi et al., 2018). In their study exploring the reflections of 28 close family relatives of 18 patients who died by assisted suicide in Switzerland, Gamondi et al. (2018) noted that family members may be required to take on additional responsibilities in preparation for an assisted suicide, including within the decision-making process. Family members may play an important role in "reflecting pro-and contra-arguments about assisted suicide with the patients and pondering with them the timing of the act" (p. 1090). In their study, Gamondi et al. (2018) outlined five phases in which families participate: (a) contemplation, (b) gaining acceptance, (c) gaining permission, (d) organization, and (e) aftermath. A family member's decision to participate and provide support to the patient "appeared to be the result of a compromise between the family member's and the patient's values, with respect for the patient's decision being a common principle" (Gamondi et al., 2018, pp. 1087-1088).

Gamondi et al. (2018) found that it was during the "gaining acceptance" (p. 1089) phase, that family members began to build a strong collaboration with their loved one in regards to assisted suicide. "Gaining permission" (Gamondi et al., 2018, p. 1089) consisted of family members acting as advocates for the patient, overcoming dilemmas about their own involvement in the process, and searching for a physician to provide the necessary prescription. The recognition of the patient's unbearable suffering often triggered a transition between "gaining permission" phase and moving toward "organization" (Gamondi et al., 2018, p. 1090). "Organization" involved negotiating the

time and date or the death with the right-to-die association, planning rituals surrounding the death, and making funeral arrangements. Family members described feeling undecided about the timing of the death, and they felt that they were carrying a burden of responsibility for "actioning the patients' choice during this phase" (Gamondi et al., 2018, p. 1090). They recalled feelings of "ambivalence, distress and exhaustion" (Gamondi et al., 2018, p. 1090). In the "aftermath" phase (Gamondi et al., 2018, p. 1090), participants reflected on their experience of respecting their loved one's decision. Gamondi et al. (2018) wrote, "All participants recalled how important it had been to respect the patient's decision about assisted suicide, irrespective of their level of active or passive involvement" (p. 1090). For some, it was only after the death that they felt they had understood the patients' suffering. Overall, assisted suicide appeared to be the result of negotiations within the family circle and outside of it, and often these negotiations resulted in a sense of shared responsibility for the decision to proceed with assisted dying (Gamondi et al., 2018).

Gamondi et al. (2018) summarized that many factors contribute to how family members end up playing a role in assisted suicide. These factors include the patients' capacity to pursue their intentions independently, the family members' own beliefs and attitude toward assisted dying, the type of relationship amongst family members, and the interactions with healthcare professionals and right-to-die associations. Gamondi et al. (2018) noted that cultural specificities surrounding the complex experience of participating in assisted suicide need to be considered, suggesting that the Swiss civil model may allow patients and families greater autonomy in both decision-making and organizing assisted suicide, but that this same model may require family members to

assume a "broader moral and practical responsibility of the whole process" (p. 1093). With this in mind, they recommend that legislators and developers of clinical guidelines pay greater attention to the ways in which family members are involved in assisted dying including the roles that family members hold. Throughout the literature it is clear that family members are involved in assisted dying in unique, challenging, and potentially rewarding ways.

Integration of Family Members' Values and Beliefs

The literature highlights that family members' values and beliefs are acknowledged or integrated into the process or experience of MAiD in various ways and in differing degrees. In his study exploring the relationship between ending life by means of euthanasia for those living with AIDS in the Netherlands and complicated grief in survivors, van den Boom (1995) interviewed 60 relatives of 52 deceased AIDS patients. Participants also responded to a questionnaire. Findings indicated that most partners and family members expressed that at some point they wished that the patient would postpone the euthanasia, but all of them respected and understood the patient's decision, even when it went against their own religious beliefs.

In their study, Starks et al. (2007) found that some family members decided they could not support their loved one's choice to hasten death, and therefore these family members chose not to be present at the time of death. For others, though they did not agree with the decision to hasten death, and felt that death would be premature, they wanted to support their loved one's right to choose and decided to still be present at the time of death. One family member felt isolated from the rest of her family, wishing she could simply care for her mother until she died, without trying to control the situation, as

she felt her family was trying to do. She agreed to participate, and experienced the death as beautiful, but experienced guilt and social isolation still two and half years after the death. Starks et al. (2007) found that for some family members, a negotiation occurred regarding their role and involvement, in an attempt to support their loved one while maintaining "a clean conscience" (p. 122).

Gamondi et al. (2018) highlighted the respect family members' often showed to their loved one, even when they disagreed with their decision. They noted that "all participants reported having to overcome dilemmas concerning their involvement in assisted suicide" (p. 1089). Family members most often justified their own involvement in assisted suicide by recognizing the suffering of their loved one to be unbearable. Even when family members were reluctant to offer practical help, they sometimes still chose to be present at the moment of ingestion as an act of respect. In their study exploring the experience of supporting a loved one through MAiD, Holmes et al. (2018) found that support persons described the process from their loved one's diagnosis, to requesting MAiD, to actual death, as being a journey. Of the 18 participants interviewed, all provided emotional and practical support in their loved one's preparation for MAiD, and though several participants were initially opposed to their loved one's decision, their minds were changed as a result of witnessing their loved one's suffering. Holmes et al. noted that a few of the participants "expressed tension between supporting their loved ones and being upset about their decision to have MAiD" (p. e390). When comparing family caregivers of patients who had requested aid-in-dying with family caregivers of patients who had not pursued aid-in-dying, Ganzini et al. (2009) found that there was no

significant difference in how family members endorsed the importance of caring for the ill individual or in the degree to which they felt burdened by caregiving.

Gamondi et al. (2018) found that the numerous negotiations amongst family members, patients, and those outside of the family circle allowed for a sense of shared responsibility in the decision to pursue aid-in-dying. Family members noted that this decision was very private in nature and was believed to belong in an "intimate sphere of the person and their relationships" (p. 1090). Their data illustrates:

> the importance of building a relationship and of sharing the burden between patients and family members regarding the decision about assisted suicide. Consistent with the literature, the process toward assisted dying appeared to be as important as the event itself. (Gamondi et al., 2018, p. 1090)

They noted that the Swiss model may stand in contrast with the shared decision-making model found in the Netherlands. In their findings, Swiss families and patients seemed to make the decision for aid-in-dying by themselves and only involved right-to-die decisions in later phases. Gamondi et al. (2018) noted a "climate of relative secrecy" (p. 1092) surrounding the issue of assisted death in Switzerland, and they noted that this may have a negative influence on the bereavement process.

In their qualitative study of bereaved family members in Southern Switzerland, Gamondi et al. (2015) interviewed 11 relatives of eight patients whose loved one had died after assisted suicide. Gamondi et al. (2015) note that four relatives declined to participate in their study, stating that it would be too emotional to recall their experience. In their findings, all participants described facing moral dilemmas during the decision-making phase of assisted suicide. Of their participants, all but one were principal caregivers of their relative, actively involved in day-to-day care since their loved one's cancer diagnosis. Crucial concerns of family members included wondering if the assisted suicide

was "the right thing to do" and if the timing was "right" (Gamondi et al., 2015, p. 148). Family members also faced dilemmas around what level of involvement they would have in the process.

Gamondi et al. (2015) differentiated between "active" involvement in the decision-making phase and passive involvement (p. 148). Family members who were actively involved appeared to share a common moral position concerning assisted suicide, and therefore discussions and decision-making surrounding the procedure were more straightforward. For these family members, their dilemmas appeared to be solved during the decision-making phase or within a few months after death, as they were able to move on from their doubts with less emotional distress. For family members who had more passive involvement, the decision to participate in assisted dying ethically challenged their own moral values, sometimes causing them to abstain from taking a practical role in the assisted suicide. For these relatives, "the burden of carrying moral dilemmas was reported as significant" (Gamondi et al., 2015, p. 148). While in some cases, relatives offering opposing views created opportunity for conversation surrounding the pros and cons of assisted suicide, in other cases, family members who did not agree with the decision were isolated from the process and were accused of being self-centered and insensible toward the patient's suffering. The family member's dilemma was considered to be a second priority when compared to carrying out the patient's wishes. In some cases, patients threatened to commit suicide when faced with opposing family members. Gamondi et al. (2015) found that when one family member began to share a common vision with the patient for assisted suicide, this served as a catalyst to begin the

process. Interestingly, as the date of the planned assisted suicide approached, the majority of relatives reported wishing for a natural death for the patient.

Gamondi et al. (2015) noted that within families, different members showed different types of involvement. Various beliefs, values, and attitudes toward assisted dying can occur even within one family. In their systematic mixed studies review, Roest et al. (2019) explained how EAS was often planned together with family members. They noted, however, that some family members preferred to stay out of the planning of EAS, letting the patient and physician choose the date based other factors such as symptom management, loss of competency and psychological suffering. In these ways, the literature points to both the variation of ways in which family members felt a part of their loved one's death and the complex challenges that can arise when attempting to integrate family members with different values and beliefs into the process and event of assisted death.

Meaning-Making for Family Members over Time

How do individuals find or make meaning in their loss of a family member who received assisted dying, and how does this evolve over time? In their qualitative study on the effects of physicians reporting euthanasia on patients and grieving family members in Holland, Ciesielski-Carlucci and Kimsma (1994) found that not reporting cases of euthanasia can prevent family members from beginning their healing process. Seven different families were interviewed about positive and negative aspects of euthanasia. Drawing on these interviews, along with an unspecified number of interviews with various professionals involved in cases of euthanasia including physicians, attorneys, and ethicists, Ciesielski-Carlucci and Kimsma (1994) provided several narrative accounts

speaking to the impact of reporting cases of euthanasia on family members. Drawing on an earlier report of van den Boom's study which suggests that complications can adversely affect family members, Ciesielski-Carlucci and Kimsma (1994) noted their concern that "not reporting cases of euthanasia may give rise to complications which would negatively impact the patient and the grieving family" (p. 153). Findings suggested that reporting cases of euthanasia allowed family members to discuss their experience openly with others. Ciesielski-Carlucci and Kimsma (1994) summarized:

> Part of the grieving process for the bereaved is recounting the story of the dying patient's last days, reliving the experience and sharing it with others. The bereaved are denied this opportunity to heal if euthanasia is kept secret since they may not speak of it. (p. 156)

By reporting cases of euthanasia, Ciesielski-Carlcucci and Kimsma (1994) suggested that complications in bereavement can be prevented as an environment of trust and openness is fostered, benefiting families, physicians, and societies.

In their study on the effects of euthanasia on bereaved family and friends, Swarte, van der Lee, van der Bom, van den Bout, and Heintz (2003) compared the grief experience of bereaved family and friends of terminally ill cancer patients who died by euthanasia (n = 189) with that of a group of comparable cancer patients who died a natural death (n = 316*)*. Patients died in a tertiary referral centre for oncology patients in the Netherlands between 1992 and 1999. Study findings indicated that the family and friends of cancer patients who died by euthanasia experienced fewer traumatic grief symptoms, less current feelings of grief, and less post-traumatic stress reactions than the family and friends of patients who had died a natural death. Though they acknowledged the limitations of non-response and the setting of their study not being representative of the deaths that occur at home, Swarte et al. (2003) concluded that grief after an assisted death

of a terminally ill cancer patient was not more complicated than it was for those whose loved one had died of natural causes. Swarte et al. (2003) hypothesized that the opportunity for family members to say goodbye to their loved one while they are generally fully aware might explain fewer grief symptoms, as well as feeling more prepared for the death due to the knowledge of how the patient would die and when. Finally, they concluded that when a terminally ill patient requests euthanasia, the patient and family members are able to openly discuss death (Swarte et al., 2003).

These findings support those of van den Boom (1995) whose study examined the association between AIDS-related euthanasia and complicated grief in survivors. When looking at this relationship, van den Boom (1995) found no significant association between the prevalence of depression in survivors and the type of death. Van den Boom (1995) concluded that "the only relationship between euthanasia and complicated grief was that when the euthanasia process was complicated, grief became complicated" (p. S182). He noted that six of the 12 cases of euthanasia in his study were considered complicated, and in two cases relatives developed serious psychopathology. These cases became complicated as a result of: (a) the patient dying the moment the injection was administered, (b) the patient remaining conscious 4-6 hours after the administration of the injection, (c) the physician asking the relative to administer the medication at the moment of euthanasia, and (d) relatives having to decide when euthanasia should occur. Relatives also found it difficult to know that their partner who was in possession of the lethal medications could self-administer it at any time. In response to these complicated scenarios, van den Boom (1995) stated, "in most cases, those complications could have been averted, had the responsible physicians been clear about their own moral position

right from the beginning or had they had better knowledge about the required dosages of the thanatic drugs" (p. S184). He suggested that euthanasia, regardless of if it is AIDS-related or not, has an impact on grief, "because death has an impact" (p. S182). Van den Boom (1995) concluded, however, that it cannot be maintained that euthanasia *will* result in complicated grief.

In Srinivasan's (2019) recent study, 22 family members who had a loved one die under Oregon's Dying with Dignity Act were interviewed about their bereavement experience. Five themes emerged from the data including: (a) general grief reactions, (b) anticipating the death, (c) sense of control, (d) level of agreement with assisted death, and (e) grief expression and stigma. Srinivasan found that all participants experienced one or more common grief reactions including sadness, anger, numbness, sense of loss, and disbelief. Because participants' loved ones received a prescription for an assisted death, family members experienced anxiety over the scheduling of their loved one's death. They also felt, however, that they were given an opportunity to be able to gain knowledge and prepare for the actual moment of death. Many participants experienced anticipatory grief. Assisted death gave family members a unique opportunity to say goodbye and to address any "unfinished business" with their loved one. With their loved one having a sense of control over their dying process, participants were in some ways more accepting of the death. Srinivasan noted, "Participants' grief reactions varied depending on their level of agreement with the loved one's decision to die an assisted death. Agreeing with the loved one's decision eased grief, creating a sense of connection and understanding with the loved one" (p. 650). Several participants noticed conflict over their loved one's decision. Reasons for conflict included religions or professional

opposition, differing opinions within families, feelings of having been responsible for the loved one's death, and a general questioning of whether assisted death was the right decision to support. Conflict "became a very significant factor in the grieving process" (Srinivasan, 2019, p. 651). Most participants were able to express their grief and disclose their loved one's mode of death, though Srinivasan noted that "most participants also self-selected who they chose to tell about the mode of death" (p. 652). Respect for their loved one's privacy, along with anticipated stigma, caused some participants to be selective about their disclosure.

Srinivasan (2019) explained that grief following an assisted death has unique features, as well as features that overlap with non-assisted death. In some ways, participants' experiences of grief overlapped with bereavement experiences following a terminal illness. For example, both scenarios offer opportunity to say goodbye, to prepare for the death, and to engage in anticipatory grief. Assisted death overlaps with death by suicide in that both involve an intentional decision to end one's life. Though most of Srinivasan's participants did not equate assisted suicide with suicide, some felt that people around them believed both forms of death were the same. These reactions were stigmatizing and affected participants' expression of grief. Stigma led some participants to experience disenfranchised grief, which Srinivasan explained, can lead to complicated grief, "which is marked by unresolved feelings that may be severe and prolonged, disrupting daily functioning" (p. 654). To summarize, Srinivasan argued that "those grieving an assisted death should be aware that supporting the law does not necessarily translate to agreement or ease with a loved one's decision" (p. 164). However,

participants who fully agreed with a loved one's decision and supported the law felt ease in their grieving process.

Starks et al. (2007) found that different types of involvement in assisted death shaped how family members dealt with regrets. For some family members, they regretted their inaction when watching their family member die an avoidably difficult death. For families that had experienced complications, moving forward and adjusting to the loss was delayed, and that resulted in symptoms of clinical complicated grief. Similarly to Ciesielski-Carlucci and Kimsma's (1994) study, Starks et al. (2007) found that maintaining secrets and not sharing the details of their stories and involvement in their loved one's assisted death kept some family members from moving ahead.

In their qualitative study, Feigin, Owens, and Goodyear-Smith (2019) used semi-structured interviews to explore the personal experience of having assisted with another person's death in New Zealand, where assisted dying is not legal. All three participants experienced consequences as a result of their involvement with the assisted death. In order to cope with the emotional and psychological impact of experiencing such significant transitions in their lives, all three participants described detaching from their experience and avoiding thoughts about the event. This was found to have detrimental effects leading to episodes of traumatic grieving, but it was beneficial in allowing completion of daily tasks for example, and coping with incarceration. Sharing stories was another way in which participants coped with their experience. Because they could anticipate their loved one's death, participants were able to be "engaged in grief work before the actual death, which served an adaptive function" (Feigin et al., 2019, p. 98). Being able to say goodbye was helpful. Experiencing the continued presence of a loved

one, and being involved in activism for the legalization of euthanasia, helped give meaning or purpose to participants' experiences. Though these aspects of assisted dying proved helpful in their grief, Feigin et al. (2019) noted that throughout the interviews, participants often referred to the grieving process as traumatic. Two participants experienced psychological conflict, feeling torn between caring for loved ones and preventing further suffering. Exhaustion and feelings of isolation and guilt impacted these primary caregivers. Participants found witnessing their loved one's deterioration, increased level of dependence, and gradual loss of control to cause feelings of helplessness. This led them to feel that with "the lack of provisions and options for their loved ones in the form of assisted dying . . . life had to be cut short before total loss of control and dependence occurred" (Feigin et al., 2019, p. 100). For these participants:

> Ending of suffering and a peaceful death were described as more important than any potential legal consequences. Participants discussed a difference between living and merely being kept alive. In particular, being kept alive for the sake of living was discussed as prolonging suffering. (Feigin et al., 2019, p. 101)

Participants viewed their lives as being shared with their loved one, and all three felt that despite the personal cost they experienced, helping their loved one to die "was the right thing to do" (Feigin et al., 2019, p. 103).

Wagner, Müller, et al. (2012) investigated the impact of witnessing assisted suicide on the mental health of $n = 85$ family members or close friends in Switzerland. Using a cross-sectional survey, full or partial Post-Traumatic Stress Disorder (PTSD), depression and anxiety symptoms, and complicated grief in family members or friends were assessed 14-24 months after their loved one had died. Using the Impact of Event Scale-Revised, 13% met the criteria for full PTSD and 6.5% for subthreshold PTSD. With the use of the Brief Symptom Inventory, the prevalence of depression was 16%, and

the prevalence of anxiety was 6%. Complicated grief was measured using the Inventory of Complicated Grief and showed that 4.9% of respondents met the criteria for complicated grief. Wagner, Müller, et al. (2012) concluded that witnessing death by assisted suicide does in fact impact the mental health of family members and friends. In comparison with an epidemiological study of elderly people (n = 570) in Switzerland (Maercker et al., 2008), which assessed the prevalence of trauma and bereavement-related stress disorders, the general elderly population of Switzerland reported lower prevalence rates of PTSD (0.7%) and subthreshold PTSD (4.2%) than family members showed in Wagner, Müller, et al.'s (2012) study. Family members in Wagner, Müller, et al.'s (2012) study had a comparable prevalence of complicated grief to that reported for the general Swiss population. Although no control group of respondents who lost a loved one by natural death was used, Wagner, Müller, et al. (2012) concluded that in their study, though assisted suicide seemed to not cause additional complications in the grief process, about 20% of their respondents experienced full or subthreshold PTSD related to their loss of a loved one through assisted suicide. Their recommendations, therefore, included informing family members about the possible consequence of witnessing assisted dying for their mental health and ensuring that right-to die organizations offer professional help focused on trauma-related symptoms.

In an earlier article based on the same study, Wagner, Keller, Knaevelsrud, and Maercker (2012) also examined the effects of perceived social acknowledgement on symptoms of post-traumatic stress and complicated grief. Using the Social Acknowledgement as a Victim or Survivor Questionnaire, Wagner, Keller, et al. (2012) sought to examine the impact of the social environment's acknowledgement of their

loved one's end-of-life decision on the mental health of study respondents. This questionnaire measures "the degree to which people feel validated and supported by their social environment following a traumatic event" (Wagner, Keller, et al., 2012, p. 383), by clustering 16 items into three subscales of Recognition, General Disapproval, and Family Disapproval. Wagner, Keller, et al. (2012) defined social acknowledgement in the context of PTSD, as "a victim's [or in in this case survivor's] experience of positive reactions from society that show appreciation of the victim's traumatic experience and acknowledge the difficulty of their situation" (p. 382).

When assessing the degree to which people felt validated and supported by their social environment, following a traumatic event Wagner, Keller, et al. (2012) found that social acknowledgement predicts PTSD symptom severity and complicated grief. By calculating the relationships of social acknowledgement with PTSD and complicated grief, Wagner, Keller, et al. (2012) found significant correlations between the General Disapproval subscale and all PTSD symptoms *(rs* = 0.50-0.56). Wagner, Keller, et al. (2012) concluded that General Disapproval seems to have the strongest impact on both PTSD and complicated grief. Noting that many of their participants reported not talking to friends, colleagues, priests, or neighbours about the way that their loved one had died, Wagner, Keller, et al.'s, (2012) findings suggested that participants may have experienced a sense of disapproval and isolation from their social environment, thereby complicating their ability to cope with the assisted suicide of their loved one. Scores from the General Disapproval subscale were positively correlated with PTSD symptoms and complicated grief, suggesting that "survivors who do not receive social acknowledgement experience more mental health problems in the aftermath of the death" (Wagner, Keller, et al., 2012,

p. 385). Wagner, Keller, et al. (2012) drew the conclusion, therefore, that acknowledgement may be an important aspect of recovery for family members who have witnessed an assisted suicide and that there may be a positive influence on the healing process when family members disclose their experience.

These findings support those of Gamondi et al. (2018), who reported that in their study, "all participants shared the reflection of having experienced a very intense process" (p. 1090). Family members felt that the assisted suicide had allowed them to acknowledge the intensity of the patient's suffering. In the "aftermath" phase of their experience, however, family members reported being careful and partial about disclosing the facts surrounding their loved one's assisted suicide, "depending on the participant's capacity for anticipating or overcoming actual or anticipated stigma" (Gamondi et al., 2018, p. 1090). Some stated that this disclosure should only occur when it was pertinent and relevant to the context of the discussion. Others chose not to disclose as a means of "retaining intimacy" (Gamondi et al., 2018, p. 1090). Gamondi et al. (2018) summarized, "Although most participants felt unable to share their story after the death, this appeared to be due largely to fears of people's possible reactions and of feeling judged" (p. 1090). Surprisingly, none of the twenty-eight relatives interviewed in this study requested or received professional support during bereavement. Gamondi et al. (2018) noted that family members in Switzerland appeared to resort to their own resources, rather than discussing their experiences with other relatives, friends or processionals. They stated that "potential negative impacts of not discussing assisted suicide may be mitigated by a trend toward more open debate in society concerning assisted dying" (p. 1092).

Gamondi et al. (2015) found that family members faced isolation in the decision-making phase of assisted suicide, as well as in the bereavement period. Many family members had promised their loved one that they would keep the assisted suicide a secret. This restricted open dialogue for the family member before and after the death. Gamondi et al. (2015) also found that family members often discussed assisted suicide in a restricted family circle, early on, before involving health professionals. Family members feared being judged or disapproved of by family members and friends, and they were concerned about the potential stigma surrounding assisted suicide. They also experienced isolation as a result of the emotional burden felt in having to recall facts and share their experience. While some participants reported a desire to share the details, the decision about who to tell was made carefully. When the loved one who died had children, family members expressed that they did not know how to explain the complex death to the children. Gamondi et al. (2015) made the interesting observation that:

> The type of involvement seems strongly correlated to the personal moral stance of the relative: a favourable position concerning assisted suicide leads to an active involvement in its procedures, and possibly to a less trouble bereavement. But secrecy and isolation seem to be unrelated to the type of involvement. (p. 151)

Regardless of their moral views on assisted dying, Gamondi et al. (2015) found that all family members seemed generally unprepared to discuss the type of death or their involvement with it. In summary, "the secret was described by many of the relatives as a heavy burden to carry" (Gamondi et al., 2015, p. 150).

Holmes et al. (2018) conducted a qualitative study using semistructured interviews at a clinic in Vancouver, BC, to explore the experience of supporting a loved one through MAiD in Canada. Eighteen support people were interviewed, with the study focusing on the initial reactions of support persons' learning that their loved one wished

to have MAiD, how their opinions about MAiD evolved over time, their experience with death itself, and their feelings after the death. In their findings, Holmes et al. (2018) noted that most of the support people were not surprised by their loved one's interest in MAiD. In some cases, discussions about MAiD occurred even prior to the loved one becoming unwell. Several participants noted a tension between supporting their loved one and being upset about their decision for MAiD. Holmes et al. (2018) explained, "interviewees felt that their sadness regarding the upcoming death of their loved one was overshadowed by hoping for the end of their loved one's suffering" (p. e390). All participants provided emotional and practical support, with some noting that "It's kind of an overwhelming process . . . you kind of take it day by day" (Holmes et al., 2018, p. e391). Though MAiD offered the advantage of being able to say goodbye to a loved one, participants also acknowledged that the planned death day was "an interesting and unusual experience and was thought to be peaceful overall" (Holmes et al., 2018, p. e391).

In their systematic review exploring grief after euthanasia and physician-assisted suicide, Andriessen, Krysinska, Dransart, Dargis, and Mishara (2019) summarized that:

> the psychosocial aftermath of this type of death is not worse than that of other types of death. Nevertheless, those bereaved may have to cope with the social perception of assisted dying and with moral and relational issues within the family. (p. 9)

As this literature has indicated, meaning-making for family members before, during, and after their loved one's death poses unique challenges, especially given one's own moral position on assisted death and one's relational and social context.

Insights from Family Members and Implications for Nurses

What insights do family members have for healthcare providers involved in assisted dying, and what are the implications for nurses? Starks et al. (2007) pointed out

that for one family in their study, the support received from a case worker meant that their 8-hour vigil at the bedside "was experienced as a spiritual event as opposed to [an] anxiety-provoking one" (p. 119). For another family, having the presence and expertise of a physician who could facilitate and attend the death meant that family members could "simply be present to witness and support" (Starks et al., 2007, p. 121). For many families, having professional support, from either an advocacy organization or a healthcare provider, was key to reassure family members and increase their comfort with their role and involvement in assisted death (Starks et al., 2007). Worries about legal consequences and social stigma associated with suicide meant that some family members experienced limited support in their bereavement, as well as isolation (Starks et al., 2007). These findings indicate that healthcare providers play a significant role in supporting family members dealing with the assisted death of a loved one.

As mentioned above, Wagner, Müller, et al.'s (2012) findings suggested that the mental health of family and friends must be considered by healthcare professionals and right-to-die organizations and that professional help including a focus on trauma-related symptoms should be offered. In addition to this, they noted that family members and friends who witness assisted death need to be better informed and prepared for the possible effects of the process on their mental health. Gamondi et al. (2015) noted that family perceived that their moral dilemmas were under-recognized by the care team. They concluded that:

> A proper recognition and assessment of the relatives' experience is needed in order to provide support during the process. Acknowledgement of the experience of family members should be an essential component of all research investigating assisted suicide. Policy guidelines in Switzerland should be developed in order to better assess family needs during assisted suicide decision making, and further

> research is warranted to investigate the impact of these guidelines. (Gamondi et al., 2015, p. 151)

By involving family members throughout the process, healthcare professionals can care for the patient while also helping family members in their own process (Ciesielski-Carlucci & Kimsma, 1994).

Gamondi et al. (2018) echoed this, suggesting that requests for assisted suicide be understood by:

> taking into consideration the life story of the patients and their family and should be interpreted in the light of the various phases leading to the ultimate decision. Beyond patient autonomy, families should be recognized as deeply involved in assisted suicide and their specific needs should be identified and addressed. (p. 1092)

They included the following recommendations: (a) identify the possible roles that family members might have in assisted suicide, (b) approach families with an acknowledgement that both patients and families have likely been considering assisted suicide for some time and their acceptance of the act may vary even within the family, (c) use biographical approaches when discussing assisted dying to encourage person-centred practice, and elicit values and life goals, and (d) investigate if family members need to undertake additional tasks related to assisted dying and address potential needs caused by this.

Though most of the literature emphasizes the role of physicians, many of the same recommendations for physicians can be applied to nurses who care for patients and their family members throughout the process of assisted dying. Starks et al. (2007) found that overall, family members who participated in an assisted death felt they were on "uncertain legal, emotional and moral grounds" (p. 127). This caused them to take on varying levels of responsibility for planning and implementing the death. At all levels of involvement, family members experienced both positive and negative consequences.

Clinicians, therefore, must consider the unique consequences for family members who participate in the process, either directly or indirectly (Starks et al., 2007). Given that all phases of caregiving are affected by assisted dying, Starks et al. (2007) suggested that family members be included throughout the process, from planning the death to receiving bereavement support. Ciesielski-Carlucci and Kimsma (1994) suggested providing education to help family members know what to expect and creating opportunities for dialogue to help family members safely share about their experience. Starks et al. (2007) concluded that new legislation surrounding hastened death should offer provisions for education family members and should acknowledge the role of family members and their needs for support.

In their qualitative multi-methods study of family caregiver perspectives exploring how to improve the MAiD process, Hales, Bean, Isenberg-Grzeda, Ford and Selby (2019) gathered experiential feedback from 11 family caregivers of patients who received MAiD in a large academic hospital in Toronto, Canada, between July 2016 and June 2017. Using surveys, focus groups, and unstructured email/phone conversations, Hales et al. (2019) grouped improvement themes into two categories: operational and experiential aspects of MAiD. In terms of opportunities for operational improvement, families reported experiencing unnecessary complexity and anxiety due to a lack of clarity regarding the MAiD process, including how to request MAiD and what to expect. Scheduling challenges due to availability of space and human resources were distressing for family members. Opportunities for experiential improvement included addressing the sense of judgment or objection family members felt from health care providers regarding their loved one's decision to pursue MAiD. For example, family members felt that having

similar questions repeatedly asked in a critical tone was hurtful, especially in the midst of an emotionally challenging process. Family members also felt burdened by the need to keep their loved one's decision private. This added stress and anxiety, as well as complexity to the grief and healing of many family members. Finally, some family caregivers noted that grief support was needed both before and after the procedure. Through this research Hales et al. (2019) concluded that "detailed guidance for how to best implement patient- and family-centered MAiD programs at the local organizational level are immature" (p. 595). Hales et al.'s (2019) findings offer insights regarding areas of improvement for the delivery of MAiD, especially in hospital settings. These recommendations offer important insights for nursing and other healthcare providers involved with assisted dying.

Opportunities and Burdens for Family Members

As has been seen throughout the literature, assisted dying appears to offer both opportunities and burdens for family members. In the study conducted by Starks et al. (2007), one family member concluded:

> It was a really good death. It was extremely bonding for our family, the people who were there. It was the strongest, most powerful experience of my life, including the birth of my children. It was more powerful than that. I think it asked more of both us, maybe, is why. (p. 119)

Planning a death provides opportunity for family members to "plan how you're going to deal with it" (p. 121). Noting that grief is a normal reaction to the death of a loved one, and that unnatural deaths can cause severe grief reactions in family members, Swarte et al. (2003) concluded that in the case of euthanasia, grief is different than that experienced in the case of an unexpected death, or a suicide, in that family members have the opportunity to "say goodbye" (p. 190). By being fully aware that the patient was dying,

family members could take advantage of opportunities to engage purposefully in closure with their loved one and to plan final celebrations and life review.

In a similar way, findings from Buchbinder et al.'s (2018) study revealed that though AID offers opportunity for advanced planning and preparation, this reality also burdened family members with pressure to ensure their loved one's final wishes were implemented. Though they noted that "AID transforms the experience of end-of-life caregiving, which is often unpredictable and uncertain" (Buchbinder et al., 2018, p. 941), caregivers reported having to suppress their own anticipatory grief and emotional response to attend to the needs of their loved one and other family members and caregivers. Buchbinder et al. (2018) summarized:

> Although AID is often presented in scholarly debates as a simple matter of individual choice and autonomy, most patients who pursue it do so with tremendous support from caregivers, who are in turn deeply implicated, socially and morally, in the process. (p. 942)

They concluded:

> Involving such caregivers in clinical discussions of AID must be sensitive to considerations of privacy and confidentiality and the relational dynamics at hand. Ultimately, however, including caregivers in education and planning, where warranted, can mitigate feelings of unpreparedness and ensure a smoother experience for everyone involved. (Buchbinder et al., 2018, p. 942)

Van den Boom (1995) hypothesized that an open awareness context can help to facilitate anticipatory grief for survivors. This finding is supported by Ganzini et al. (2009), who found that aid-in-dying families felt "more prepared for and accepting of their loved one's death and were less likely to indicate that they wanted more opportunities to care for decedent" (p. 812). Starks et al. (2007) noted that,

> On the positive side, patient interest in a hastened death prompted open communication about dying and facilitated closure and life review. When planning occurred, families had an understanding of how their loved ones

> conceptualized a "good" death and ideas about how to make it happen. On the negative side, discomfort with those plans meant some families pulled back and distanced themselves by withdrawing from the caregiving context. (p. 126)

With these potential opportunities, Starks et al. (2007) found that the process of hastened death also added several dimensions to family members' personal suffering. These included tensions surrounding the timing of death, worry about legal issues, and letting go of a desire to care for a loved one through the dying process. Van den Boom (1995) considered that family members might doubt the rightfulness of the moment of death, or the severity of suffering, leading to an adverse impact on grief. As Roest et al. (2019) summarized:

> Several qualitative studies describe how family members struggle with conflicting feelings during euthanasia decision-making. While they wish for the patient's suffering to end, and regardless of personal view on EAS, they often considered EAS to be too early, or too definitive. (p. 13)

This highlights the complexity of experiences described by family members whose loved one has received assisted dying.

Identified Gaps in the Literature

Through this literature review, several gaps in research can be identified. Mainly, little research has explicitly focused on understanding the involvement and experience of family members with assisted dying. Though the above studies offer some insight into aspects of family member experience and involvement, contextual factors unique to different jurisdictions make it difficult to generalize any findings. At the time of this initial literature review, no studies had examined how family members experience MAiD in Canada.

From their recent systematic review exploring grief after euthanasia and physician-assisted suicide, Andriessen et al. (2019) noted that, to date, research in this

field has focused on various aspects including moral and ethical challenges, public acceptance, legal status, epidemiology of euthanasia and PAS, views of individuals requesting medical assisted dying, family involvement in end-of-life decision-making, and the perceptions of physicians and other professional caregivers. They noted that the lack of research regarding the effects of euthanasia and PAS on those who are bereaved stands in contrast with the large number of research studies exploring bereavement following deaths by suicide or other causes. Aware of the growing movement to legalize assisted death in more states, Srinivasan (2019) argued, "It is, therefore, increasingly important to understand the experience of those grieving an assisted death, a relatively 'new' type of death, as it can prepare grievers for what to expect and can help professionals with providing grief support" (p. 647).

In their systematic mixed studies review exploring the involvement of family in the Dutch practice of euthanasia and PAS, Roest et al. (2019) noted that only 14 studies "had family members themselves as study participants" (p. 1). When family members are interviewed, it is often done to gain understanding of the patient experience or the care provided by physicians (Buchbinder et al., 2018). According to Buchbinder et al. (2018), with an evolving landscape on assisted dying, research agendas are beginning to move "from questions about attitudes and moral permissibility to questions about implementation and clinical practice" (p. 936). They noted, however, that although literature is beginning to examine lay experiences with AID, most of these studies have not been used to focus directly on the caregiver experience. They stated:

> Less is known about the direct experience of caregivers in supporting a loved one through the process of AID. Yet death is fundamentally social, and research conducted in other end-of-life contexts demonstrates not only that families mediate the patient's end-of-life experience, but also that caregivers' experiences

> of stress, grief, and preparedness during a loved one's dying process are legitimate targets in their own rights. (Buchbinder et al., 2018, p. 936)

Though research has pointed to the importance of taking the family members' perspectives into account when creating policies, clinical guidelines, and practice changes, few recommendations are provided for how these perspectives might be incorporated. Though the role of family members is highlighted, the question of should we be worried about relatives gaining too much influence in the process of MAiD is also presented (Snijdewind et al., 2014). Based on the literature, family members take on different roles and caregiving responsibilities when a loved one requests assisted dying. This diversity of family members' involvement demands further exploration (Gamondi et al., 2018).

Hales et al. (2019) argued that "the road to legalization of [MAiD] across Canada has largely focused on legislative details such as eligibility and establishment of regulatory clinical practice standards. Details on how to implement high-quality, person-centered MAiD programs at the institutional level are lacking" (Hales et al., 2019, p. 590). How do our policies and legislation accommodate the experience of family members, and what risks are associated with this? How much weight should the experience of family members carry, especially when it is contrary to that of the patient? The logistics of including family members appear difficult, and there is no consensus on how the role of relatives is defined, evaluated, or welcomed. Across the literature, researchers recognize the dominance of an individualized approach to assisted dying. Though this is challenged, recommendations for honouring both the patient's autonomy and the perspective of family members, while recognizing the relational realities of MAiD, are few. Is MAiD legislation meant to be physician-centered, person-centred, or

family-centered, or is there an alternative approach, allowing for the values of everyone involved to be recognized?

In addition to drawing attention to how family members experience assisted dying across jurisdictions globally, research is also needed to understand this experience in the Canadian context. To my knowledge, at this time, only two studies have explored the experience of family members in relation to MAiD in Canada. Noting that their study may have missed perspectives of those who were less supportive of MAiD, and that the variety of experiences of MAiD in other locations and settings outside of Vancouver, BC may be not captured, Holmes et al. (2018) suggested expanding interviews to other parts of Canada and using purposive sampling to capture the views of those who may be more ambivalent or opposed to MAiD. Hales et al. (2019) explained that the generalizability of their study's findings may be limited with respect to those who have a nonhospital MAiD experience. Even with these studies, it remains largely unknown if the experience of Canadians is similar or different to those of family members around the world. With minimal research investigating how family members have experienced MAiD in Canada since it was legalized in June 2016, policymakers and healthcare providers have had little evidence to draw on. It has, therefore, been the goal of this thesis to address this gap, by providing insight into family members' experience of MAiD and considering implications for healthcare.

Chapter Summary

In this chapter I have presented the current state of knowledge about family experience of MAiD. To do so, I designed and applied a search strategy that yielded 16

articles. Of these, it is only since 2018 that research has begun to address MAiD in the Canadian context. In the next chapter, I present the Methods employed for this thesis.

CHAPTER THREE: METHODS

As I described in Chapter One, this qualitative study was grounded in a feminist tradition and used the *Listening Guide* (LG), which is a Voice Centered Relational Approach (also known as Voice-Centered Relational Method; Gilligan et al., 2003). In this chapter, I discuss underlying paradigmatic assumptions and steps of this qualitative method. I provide descriptions of recruitment, sampling, and data collection procedures, as well as limitations of this study. Finally, I present measures taken to ensure scientific quality, along with ethical considerations for this study.

Study Design

As previously noted, discussion surrounding MAiD often centres on ethical, moral, and legal considerations. Previous research has suggested that family members experience tension in deciding how they will participate in the process and experience of MAiD in a way that honours their loved one and considers his or her suffering and aligns with the family members' own personal values and beliefs. Recognizing the complex dimensions of participating in and/or witnessing assisted death, the literature suggests this process evolves for family members throughout the decision-making, planning, event itself, and mourning period. Though one family member may decide to participate in assisted dying and may report positive feelings associated with their involvement, that same family member may also express doubt regarding their participation or may wish that the event would have been postponed. Given both the diversity of how family members are involved with and experience MAiD, and the wide range of reflections within one family members' own experience, the LG as a method creates space for this complexity. It acknowledges the distinct voice of each person, and it provides a method

of psychological analysis that "draws on voice, resonance, and relationship as ports of entry into the human psyche" (Gilligan et al., 2003, p. 157).

The Voice Centered Relational Approach has been positioned within various theoretical perspectives including feminist standpoint theory, literary, narrative, and relational theories (Bright, Kayes, Worrall, & McPherson, 2018). Based on a relational ontology (Doucet & Mauthner, 2008), the approach focuses on relational aspects of the phenomenon being studied, including the relationships between the multi-layered voices within the research participant, between the participant and those around them, and with the broader context. Knowledge is contextual and multi-layered, and it is viewed as a social construction (Mauthner & Doucet, 2003). Both the participant and the researcher are socially located, and this influences how researchers interpret the individual's experience and how they actively construct knowledge by listening to particular voices in the transcripts (Doucet & Mauthner, 2008). Knowledge construction is both responsive and relational, demonstrating as Doucet and Mauthner (2008) explained, that ontology and epistemology are closely entwined. Koelsch (2015) explained that feminist researchers have been drawn to qualitative methods as a way of rejecting positivist ontological and epistemological assumptions, which emphasize rationality and reduction. Within the Voice Centered Relational Approach, the LG offers an alternative means of data analysis to that of traditional coding, which can reduce complex data to predetermined categories (Koelsch, 2015).

As an analytic approach, the LG recognizes the "collectivity of different voices that compose the voice of any given person—its range, its harmonies and dissonances, its distinctive tonality, key signatures, pitches, and rhythm—is always embodied, in culture,

and in relationship with oneself and with others" (Gilligan et al., 2003, p. 157). Although the LG originated within psychology, it can be applied more broadly, as every person has a voice that illumines or makes visible an inner world that is otherwise invisible to others (Gilligan et al., 2003). The method comprises a series of steps that allow the researcher to tune in systematically to the many polyphonic voices embedded in an individual's expressed experience (Gilligan et al., 2003). Bright et al. (2018) cautioned that the LG functions more as a research framework rather than as a "fixed prescription" of how research must be conducted (p. 2).

Assumptions held within the method are that: (a) human development occurs in relationship with others, meaning that our sense of self is "inextricable from our relationships with others and with the cultures within which we live" (Gilligan et al., 2003, p. 157); and (b) the psyche is layered in nature, and these layers are expressed with a multiplicity of voices. Developed by Gilligan and Brown, the method emerged in the 1980s, as a means of analyzing qualitative data in a way that did not reduce the complexities within the human psyche into one single static code or category, as other qualitative methods at the time were doing (Gilligan, 2015). After turning their work into a guide that researchers could follow, Gilligan (2015) changed the named from *the reading guide* to *the listening guide* in 1990. The method has now been in use for over 30 years. Built on the clinical methods of Freud, Breuer and Piaget, which emphasize the importance of allowing the person interviewed to lead the discussion, the method also draws on literacy theory and the language of music, which uses terms such as voice, resonance, counterpoint, and fugue. Joining with feminist researchers, cultural psychologists and psychological anthropologists, the LG emphasizes listening to the

interviewee's voice, and it cautions "voicing over the truth of another" (Gilligan et al., 2003, p. 158). Gilligan and Eddy (2017) noted that the LG is both a method and a methodology, reframing research as process of relationship, thereby asking the researcher to "be fully attentive and present in the moment, to listen closely and actively respond, to engage rather than disengage. In this way it challenges us to rethink what we mean by objectivity" (p. 80).

LG is made up of a series of sequential listenings, "each designed to bring the researcher into relationship with a person's distinct and multilayered voice by tuning in or listening to distinct aspects of a person's expression of her or his experience within a particular relational context" (Gilligan et al., 2003, p. 159). The researcher must remain actively present during each step, engaging with the "unique subjectivity" of each participant (Gilligan et al., 2003, p. 159). Brown and Gilligan (1993) emphasized that the voice of the researcher is explicitly brought into the process. In listening to the participants, these questions about voice are considered: "Who is speaking and to whom, telling what stories about relationship, in what societal and cultural frameworks" (Gilligan et al., 2003, p. 159). Instead of reading or quantifying the text into codes as traditional qualitative methods suggest, the LG emphasizes the *listening*, inviting the listener to tune into the story on multiple levels. There is no one, single representation of a persons' experience, and therefore, this method uses a series of listenings to recognize that the psyche is contrapuntal, with simultaneous voice co-occurring. Drawing on the work of Jonathan Shay, Gilligan and Eddy (2017) cautioned researchers to be careful to not reduce listening into "intellectual sorting" (p. 77). This method assumes the participant is the expert of their experience. To truly listen, researchers must come from a

place of genuine curiosity and "not knowing," being open to surprise and discovery (Gilligan & Eddy, 2017, p. 77). This form of listening creates trust, respect, and engagement between the participant and the researcher (Gilligan & Eddy, 2017).

The Four Steps of the LG

Four steps make up the analysis process of the LG. Step 1 involves the researcher, or listener, "Listening for the plots" and responding to the interview (Gilligan et al., 2003, p. 160). Similar to other qualitative forms of analysis, this step involves getting a sense of what is happening, where, with whom, and why. Dominant themes are noted, as well as repeated images and metaphors, contradictions and absences. Larger social and cultural contexts are identified. The aim is to be descriptive, to be specific, and to stay close to what has actually been said, using the participants' words wherever possible (Gilligan & Eddy, 2017). In this step, researchers identify, explore, and make explicit their own subjectivities, thoughts, and associations with the narrative being analyzed. Recognizing that a researcher can never be simply "neutral" or "objective" as an observer, this step allows the researcher to document their own experience and to respond to what is being said and by whom, thereby encouraging reflexivity (Gilligan et al., 2003).

Step 2 focuses on the voice of the "I" who is speaking, by constructing "I-poems." This step is essential in a relational method as it forces the researcher to tune into the participant's voice and to hear how this person speaks about themselves before the researcher talks *about* the person (Gilligan et al., 2003). I-poems are constructed by selecting every first-person "I" statement in a passage along with important verbs and accompanying words, and placing these in sequence, with each "I" phrase on a separate line. The I-poem "picks up on an associative stream of consciousness carried by a first-

person voice, cutting across or running through a narrative rather than being contained by the structure of full sentences" (Gilligan et al., 2003, p. 163). Several different passages are selected for each participant, with each creating a separate I-poem.

Step 3 brings the analysis back into the context of the research question by the researcher "listening for contrapuntal voices" (Gilligan et al., 2003, p. 164). This step draws from the musical form of counterpoint, where multiple melodic lines are combined and played simultaneously, moving in relationship with one another (Gilligan et al., 2003). In this step, the researcher's questions shape each listening in an iterative process, where different voices within the interview are identified and sorted. This listening allows for "the possibility that some of these voices may be in harmony with one another, in opposition to one another, or even contradictory" (Gilligan et al., 2003, p. 165). Gilligan (2015) explains that this step picks up tensions, harmonies, and dissonances between various voices, allowing the listener to hear nuance, modulations, and silence. While reading and re-reading the transcripts, each identified voice is underlined in a different colour, providing a visual means of viewing the relationship between voices (see Appendix D).

In the fourth and final step, the researcher composes an analysis, pulling together what has been learned through the entire process. Questions asked in this step include, "What have you learned about this [research] question through this process and how have you come to know this? What is the evidence on which you are basing your interpretations?" (Gilligan et al., 2003, p. 168). Gilligan and Eddy (2017) suggested asking, "What was surprising? Was there a 'wow' moment in the interview or within the process of the listenings? If so, what was it and why did it wow you?" (p. 79). After

gathering the evidence through the guided listenings, the researcher brings in their own voice as composer of the analysis, clearly linking the evidence to their interpretation (Gilligan & Eddy, 2017). With multiple participants, these analyses can then be examined in relationship to one another, noting the similarities and marked differences between them.

As the LG method "offers a way of illuminating the complex and multilayered nature of the expression of human experience and the interplay between self and relationship, psyche and culture" (Gilligan et al., 2003, p. 169), the use of this method ensures that the complexity of family members' experience of MAiD is acknowledged and honoured in my research design. In their use of the LG, Doucet and Mauthner (2008) explained that the way in which narratives of participants are reflexively read depends on the researcher's particular discipline and theoretical orientation. For example, they bring with them the basic grounded theory question of "What is happening here?" and they combine this with elements from narrative analysis (Doucet & Mauthner, 2008, p. 405). They suggested that the LG provides an interpretive method that combines a reflexive and multi-layered approach to knowing narrated subjects. In order to honour the complexity of family members' experience with MAiD, this multi-layered approach proves necessary. For the reason, it was important to include a member of another health-related discipline on this research committee. By having my second reader bring his experience as a Registered Psychologist who works with clients in the midst of grief, the interpretation of this study's findings was broadened beyond my own perspective and discipline. In this way, the LG as a method was supported in a team-based research approach.

The LG has been used across a wide range of contexts and is applicable wherever there is a first-person voice (Gilligan & Eddy, 2017). Gilligan and Eddy (2017) noted that the LG "tunes our ear to the multiplicity of voices that speak within and around us, including voices that speak at the margins and those which in the absence of resonance or response, tend to be held in silence" (p. 76). Koelsch (2015) echoed this, noting that the I-poems used in the LG have proven powerful to illuminate subjects that are taboo, controversial, or difficult to discuss. Though few studies within the discipline of nursing have used the LG, the method creates a unique way of approaching this study that seeks to hear the voices of family members in relation to their experience of MAiD and to incorporate "participant experience as a contributor to professional knowledge" (Petrovic, Lordly, Brigham, & Delaney, 2015, p. 10).

There are several important considerations in using this method. First, as Gilligan (2015) explained, "knowing that people often and for a variety of reasons do not say what they really feel and think, or don't know what they're feeling or thinking, poses a challenge to researchers, and especially researchers working with qualitative methods" (p. 73). Viewing this challenge as a relational one, the LG responds to it by encouraging the researcher to question normative assumptions that could otherwise be taken at face value, thereby encouraging the participant to say what they know or feel (Gilligan, 2015). Gilligan summarized that "a good method is also an ethical method" and "the ethics of research becomes an ethic of relationships" (p. 73). The relationship between researcher and participant therefore becomes a key element of the research process.

Second, the method has been criticized for not providing enough guidance in regards to the logistical implementation and application of the LG to one's data set and

research scope (Petrovic et al., 2015). Specifically, little direction is given regarding how to incorporate one's reflexive account within one's data analysis and final research write-up (Petrovic et al., 2015). In order to remedy this, Petrovic et al. (2015) wrote about their own experience of using the LG. They advised, "researchers must be cognizant of the following elements that make up the foundation of this complex qualitative method: time and patience, continuous reflective thought, and the faith that the connections are embedded within the layers" (Petrovic et al., 2015, p. 9). They went on to explain that the LG is:

> an adaptable research method that unearths the previously unnoticed and unheard voices . . . The qualitative research process is neither black and white nor straightforward. Instead, it thrives in the gray regions that are filled with nuance, detail, and richness. It is the process of unearthing these dynamic grey regions that are the most challenging and most rewarding. (Petrovic et al., 2015, p. 10)

The LG is not a cookie-cutter approach, and it must be used with an awareness of the relationships between and amongst the researcher and participant.

For this study, the four steps of the LG proved very effective in uncovering the complexities of family members' experience with MAiD. In step 1, I "listened for the plots," by listening to each participant's audio recording and then reading and re-reading their transcripts. As I read, I noted significant events, characters, repeated phrases, and contextual elements. I identified dominant themes for each participant, and I made note of important quotations to support each theme. After listening, I reflected on my own experience of hearing each participant's story. I noted questions, impressions, felt sensations, and any conflicting values I noted between my own perspective and that of my participant. Step 2 allowed me to focus on what my participants were actually saying. I highlighted each "I" phrase throughout each transcript. While I constructed some

portions of I-poems in this step, it was not until I completed step 3 that I felt I could finalize the I-poems for each participant. Step 3 involved listening for contrapuntal voices. To do this, I identified several dominant voices for each participant. Again, I highlighted these emerging voices throughout each transcript, noting places where multiple voices came together and places where only one voice was heard. These voices informed my writing of I-poems in step 2. The fourth step led to my own composition of a fugue, where I pulled together what I had learned from all of my participants. I then linked my participants' voices with my own interpretation of the findings. In following these four steps and by being deeply immersed in the data, I was able to see, hear, and appreciate the complex and multilayered experience of my participants.

Sampling and Recruitment

Though typically applied to data obtained from individual in-depth interviews or focus groups, as an analytic tool, the LG does not provide explicit direction for interviewing (Koelsch, 2015). In qualitative research, study participants are not completely pre-specified, and their selection is emergent, driven to a great extent by conceptual requirements, as opposed to representativeness (Polit & Beck, 2012). In this case, I used purposive sampling to ensure a range of variation in family member experiences was represented in the data. Purposive sampling was done by "selecting cases that will most benefit the study" (Polit & Beck, 2012, p. 517). To do this, after gaining approval from Trinity Western University's Human Research Ethics Board, I began recruitment by contacting four hospice societies in British Columbia's lower mainland and by reaching out to Dying With Dignity Canada. Information about the study along with contact information inviting people to participate was given to these

agencies to disperse when they determined appropriate based on their relationship with bereaved family members. A poster with information about the study was also posted on social media platforms and emailed to several spiritual health practitioners in the lower mainland. Potential participants contacted myself through email or telephone to indicate their interest in participating and provide contact information (see Appendix E). Upon contacting the individual in response to their interest, I asked them several pre-screening questions, not included in data collection, to assess if the individual met the eligibility criteria and would potentially benefit from participating in the study (see Appendix F). Eligibility criteria for being including in the study included the following: adults >18 years old, who have had a loved one receive MAiD in Canada. Recruitment efforts focused on ensuring geographical representation across Canada. I conducted three face-to-face interviews in mutually agreeable locations, including one participant's home and available offices at the University. In addition, I conducted four telephone interviews with participants located outside of British Columbia.

Polit and Beck (2012) noted that in qualitative research, "sampling decisions are not guided by a desire to generalize to a target population," but rather the goal of most studies "is to provide a contextualized understanding of human experience through the intensive study of particular cases" (p. 524). As Thorne (2016) wrote:

> While most patients might fit a dominant pattern, my professional mandate [as a nurse] requires me to always be seeking that new nuance on diversity that might compromise an individual patient's care or point me to a variant on standard approaches. (p. 107)

Thus in reflecting on the concept of data saturation, Thorne explained:

> in the disciplinary context of health research, the idea that one would stake a claim that no new variation could emerge is antithetical to the epistemological foundations of practice knowledge, where it is more appropriate to recognize the

> inevitable forward progression of that which we are discerning through empirical means. (p. 107)

With this in mind, recruitment and sampling were done purposefully, with the goal of hearing from various perspectives regarding family members' experience of MAiD. In order to meet this goal, seven participants were included from across Canada, representing British Columbia, Manitoba, Ontario, and Nova Scotia. All participants, when asked, described themselves as spiritual in some way, with only one identifying with an organized religion. Characteristics of the sample are provided in Table 1. A narrative describing each participant's story introduces Chapter Four.

Data Collection and Analysis

This study utilized semi-structured face-to-face or telephone interviews lasting approximately one hour. A written interview guide was prepared (see Appendix G), with probes designed to elicit more detailed information and to provide participants with opportunity to provide "rich, detailed information about the phenomenon under study" (Polit & Beck, 2012, p. 537). The interview was designed to "encourage participants to talk freely about all the topics on the guide, and to tell stories in their own words" giving freedom to "provide as many explanations or illustrations as they wish" (Polit & Beck, 2012, p. 537). A similar data collection method was used in several of the studies obtained in the literature review. Interviews were audio-recorded and transcribed verbatim. I analyzed the data using the previously explained LG method.

As presented in the next chapters, participants spoke in detail of their journey through their loved one's illness, with many reminiscing about the days before their loved one became sick. Participants told stories of how they met their loved one and shared

Table 1

Demographic characteristics of sample (n = 7)

Participant	Age	Gender (Self-identified)	Level of Education	Ethnicity (Self-identified)	Relationship to Loved One	Diagnosis of Loved One	Location of MAiD
Jeoffrey	41-65	Male	College	"English/Irish"	Spouse	Cancer	Transferred from hospice to non-healthcare facility for procedure
Tabitha	41-65	Female	College	"European"	Spouse	Cancer	Palliative unit
Landon	65+	Male	College	No response	Spouse	Chronic disease	Home
Deborah	65+	Female	Graduate studies	"Irish"	Spouse	Chronic disease	Home
David	65+	Male	Graduate studies	"Anglo-Saxon"	Spouse	Chronic disease	Home
Sandra	65+	Female	Diploma	"English/Scottish"	Spouse	Chronic disease	Nursing home
Megan	26-50	Female	University	"English/Scottish/ Mennonite"	Daughter	Cancer	Transferred to a facility providing MAiD

showed me the slideshow that they played at their partner's memorial. Many spoke with great emotion recalling their loved one's deterioration of health and their process of saying goodbye. Multiple participants cried as they remembered their final moments with their loved one. One participant expressed anger and frustration with the way their loved one managed their decision to receive MAiD. Participants were grateful for the opportunity to tell their story and reflect on their season of grief, with several saying that the interview experience made them feel closer to their loved one. Each interview was a privilege to be a part of.

Scientific Quality

To ensure scientific quality throughout my study, several strategies were utilized. A key feature of this methodology is its emphasis on researcher reflexivity. According to Polit and Beck (2012), reflexivity:

> involves attending systematically and continually to the context of knowledge construction—and, in particular, to the researcher's effect on the collection, analysis, and interpretation of data. Reflexivity involves awareness that the researcher as an individual brings to the inquiry a unique background, set of values, and a social and professional identity that can affect the research process. (p. 589)

The LG encourages researchers to thoughtfully include their own voice throughout the analytic process (Petrovic et al., 2015).

Remaining aware of the researcher's position of power in the researcher-participant relationship, Brown and Gilligan (1993) encouraged researchers to continually ask themselves the following questions:

> In what ways do we identify with or distance ourselves from this person? In what ways are we or our experiences different or the same? Where are we confused or puzzled? Where are we certain? Are we upset or delighted by the story, amused or pleased, disturbed or angered? (p. 27)

Mauthner and Doucet (2003) explained that the researcher reads the narrative with her own background, history, and experiences. As a Registered Nurse (RN) working in palliative care, my interest in this topic has developed as a result of many conversations with dying patients, their family members, and my colleagues. I have found that the processes of death and dying require all of us to consider our own beliefs, values, and practices. Recognizing my own biases' and experiences has been critical in ensuring scientific quality throughout this study, and it is also important for the sake of the relational aspect of this methodology. My efforts to listen to the varying voices of my participants were key in helping ensure I avoided objectifying my participants or their experience (Gilligan et al., 2003).

In order to do this, reflexive journaling was used regularly throughout data collection, analysis, and writing. Mauthner and Doucet (2003) noted that reflexive writing provides a means of addressing potential prejudices and personal factors that may influence data analysis. Ongoing reflexivity helps to maintain transparency and acts as an important validity check for the interpretations that arise (Mauthner & Doucet, 2003). Specifically in step 1 of the LG, where researchers "listen for the plot," the method "directs researchers to locate themselves in relation to the data and explore their own feelings and thoughts about the persons they have listened to and the material gathered" (Gilligan, 2015, p. 71). The reflexive writing that begins already in Step 1 of the process is carried through into Step 4, when the analysis is composed. Throughout the process the LG:

> prompts the researcher to listen to his or her own voice, to distinguish it from the voices of the research participants, and to be aware of countertransference or reader response so as to avoid as far as possible projecting one's feelings and thought onto others, or in writing up the research, ventriloquizing or speaking

> through others, voicing over their voices, or using them to express what the researcher want so say. (Gilligan, 2015, p. 71)

By remaining reflexive, judgment is replaced with genuine curiosity, positioning the researcher to focus on discovering what is unknown and to truly listen to the participant's voice (Gilligan & Eddy, 2017).

Throughout the process of data collection, analysis, and writing, I engaged in reflexivity in several ways. First, I engaged in reflexive writing, jotting down how I experienced each interview, how I felt afterwards, and any content that surprised me or made me feel frustrated or confused. After several interviews, I discussed my own reflections with nursing and counselling colleagues. I met with my committee regularly, sharing with them how the study was impacting me personally and professionally. This process forced me to become aware of assumptions I hold regarding end-of-life decision-making and the "right" way to provide care to family members. As someone who has taken more of a caretaking role in my own family, I was impacted by the ways my participants chose to engage their family members. I felt frustrated when they described the times they felt forced to take on certain family roles. I tried to remain open to the idea of MAiD throughout this entire process, and I worked diligently to speak about my study in a way that honoured the complexity of experiences related to MAiD. My intent throughout the entire process has been not to land on whether MAiD is "right" or "wrong," but rather to honour the stories of the people willing to share them with me and do my part to ensure that if MAiD is done, it is done well.

One way my voice made its way into the analytic process was by using the metaphor of a fugue to convey study findings. As a musician, I was immediately drawn to the contrapuntal aspect of the LG, appreciating the movement and relationship between

voices in the data. By using this metaphor, I was able to further appreciate and acknowledge the complex relationship that exists between a loved one and their family members, along with all of the other influencing factors, structures, and people in their lives. From my experience as a palliative nurse, I was tuned to hear the tensions felt by so many family members as they navigate their final days and moments—juggling multiple emotions, responsibilities, relationships, and concerns. The fugue metaphor offers a visual representation of this juggling. Having studied and performed various fugues on the piano, I know that the tensions, harmonies, and dissonances throughout the fugue can sound awkward, especially when voices are heard independent of one another. A remarkable moment occurs in a fugue when these voices are all placed against each other, resulting in a beautiful countrapuntal movement—one which could not have happened without allowing the voices to exist and move independently. My hope for this study has been to hear and honour the complexity of family members' experience. The fugue that resulted as a representation of this study's findings is a composition which seeks to highlight both the individual distinctive voices, as well as the overall complex picture that evolves as a result of careful attention to relationship. By using the metaphor of a fugue, I was able to bring my own voice into the writing process, staying true to the approach of the LG.

In addition to reflexivity, several other steps were taken to ensure scientific quality. By having the second reader for this thesis be a member of the counselling psychology discipline, the transferability of this study's findings are increased. Peer debriefing, where peers with experience in the method and phenomenon review and explore various aspects of the study, enhances the quality of the study (Polit & Beck,

2012). This was done by consulting with my thesis supervisor and second reader throughout the research process and through dialogue with other palliative care nurses and members of the interdisciplinary team throughout the process. Preliminary findings were presented at various venues and to different disciplines including an interdisciplinary conference on person-centred care, an online webinar group of MAiD researchers across Canada, and a group of third year nursing students. These presentations created opportunity to assess for resonance with the findings and to delve deeper into the meaning of these findings through dialogue. An audit trail was maintained, which included rich descriptive field notes and record-keeping of decisions and reflexive notes (Polit & Beck, 2012). By recruiting participants from various agencies, efforts were made to assess for "cross-site" consistency in the findings (Polit & Beck, 2012, p. 590). This use of space triangulation serves to help "capture a more complete and contextualized portrait of key phenomena" (Polit & Beck, 2012, p. 590) and to support construct validity (Lather, 2003). As the study has aimed to consider implications from hearing family members' perspectives for nursing practice, catalytic validity, or the degree to which the research process can bring about change (Lather, 2003), has also been emphasized. Finally, with a commitment to transparency, reflexivity, and participant-driven inquiry, this study has aspired to be of high scientific quality and trustworthiness (Polit & Beck, 2012).

Limitations of the Study

There are several potential limitations of this study. First, due to the small sample size, variation of perspectives in the selected population may not have been captured in a full sense. Second, as the study is voluntary for participants, it is possible that non-

response may have impacted the study findings (Polit & Beck, 2012). In this case, those who were experiencing more severe symptoms of grief may have been less likely to volunteer (Swarte et al., 2003). Those who felt their experience was very positive or very negative may have been more likely to participate. Due to eligibility criteria and ethical considerations, those experiencing psychotic symptoms or suicidal ideation were excluded from participating in the study. These factors may have influenced the findings. Finally, as the study was aimed at interviewing family members whose loved one has received MAiD, the perspectives and experiences of family members whose loved one requested MAiD but did not receive it, for various reasons, are not included in the study. This may have impacted overall study findings, as the perspectives of these family members was not represented.

Ethical Considerations

Approval from Trinity Western University's Human Research Ethics Board was obtained prior to commencing the study. After explaining the purpose of the study and completing the pre-screening questions to confirm that the participant met the eligibility criteria and believes they would benefit from participating, I asked each participant to sign an informed consent form (see Appendix H). Participants were informed that they could withdraw from the study at any time. Throughout the thesis, participants are identified using a pseudonym. As previously mentioned, interviews were audio-recorded, transcribed verbatim, and stored as de-identified documents on OwnCloud, a password-secured online data storage site. Hard copies of transcripts used for analysis were de-identified and stored in a locked filing cabinet. Transcription was done by a contracted transcriptionist who was required to sign a confidentiality agreement. At the completion

of the study, all electronic data will be kept for five years on a password protected computer. Hard-copies containing data will be shredded. Thesis committee members will have access to the transcribed data. Finally, identifying information about health authorities, healthcare professionals, or healthcare facilities are not named in the study.

The Tri-Council Policy Statement (TCPS; Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014) stated that: "Because research is a step into the unknown, its undertaking can involve harms to participants and to others . . . A proper ethical analysis of research should consider both the foreseeable risk and the available methods of eliminating or mitigating the risk" (p. 21).

The TCPS (2014) explained that potential harms may be minimal and transient or may be more substantial and longer lasting. Given the recent loss of a loved one experienced by study participants, considerations for how this study might impact family members were taken into account when choosing the selected methodology, which emphasizes the participants' voice while maintaining an openness to have the participant share as they feel comfortable. Previous studies that have investigated family members' experience of assisted dying have demonstrated that potential stigma and silencing of voices has negatively impacted family members in their grieving process. This study, therefore, has created opportunity to benefit family members by providing an avenue to discuss their experience. In addition to this, several family members acknowledged the felt satisfaction of knowing that their experience may indirectly impact nursing practice, which could be of benefit to families and society in general, as MAiD is implemented across Canada.

The TCPS (2014) explained that *minimal risk* research "is defined as research in which the probability and magnitude of possible harms implied by participation in the research is no greater than those encountered by participants in those aspects of their everyday life that relate to the research" (p. 22). The potential risks of participating in this study, therefore, were minimal. Measures taken to reduce risk included allowing participants to voluntarily self-select. A pre-screening interview offered further information about the study to family members who were interested in participating. Potential participants were asked questions about their past mental health and current functioning prior to arranging an interview. This data was not included in the study. No participants reported psychotic symptoms or recent or current suicidal ideation; however, if they had, they would have been excluded from participating in the study. Those who met the eligibility criteria were made aware that they could discontinue the interview or withdraw from the study at any time. They could also request to have their data removed from the study findings, prior to publication. Finally, a debriefing script was used at the end of each interview, offering information about counselling services to all participants (see Appendix I). In these ways, risks to participants were minimized, while attempts to provide a helpful and meaningful opportunity to reflect on and share one's experience were offered.

Chapter Summary

A Voice Centered Relational Approach framed this qualitative study, which examined how family members experience MAiD. Recruitment strategies included the use of purposive sampling, and data collection consisted of seven semi-structured interviews. The LG, an analytic tool, was used by the researcher to listen for the

polyphonic voices embedded within each participant's narrative. Attention to reflexivity, space triangulation, construct validity, and catalytic validity has served to ensure scientific quality. Finally, by receiving approval from Trinity Western University's Human Research Ethics Board and by taking care to minimize potential risks to the participants, this study has met and maintained ethical requirements.

CHAPTER FOUR: FINDINGS

In this chapter, I present the findings of the study, drawing on the metaphor of a fugue. As described in Chapter 3, the *Listening Guide* (LG) as a method makes use of concepts of polyphony and counterpoint by listening for different voices spoken and unspoken by participants. The *listenings* used in this method allow for "the possibility that some of these voices may be in harmony with one another, in opposition to one another, or even contradictory" (Gilligan et al., 2003, p. 165). As Gilligan (2015) explained:

> Listening for contrapuntal voices thus picks up the tensions, the harmonies and dissonances between different voices, and underscores the musical aspect of listening where the goal is to listen for nuance, for modulations and silence . . ., to resist binary categories, and to hear complexity rather than flatten the data. (p. 72)

It is with recognition of the multiplicity of voices in each of the research participants, as well as amongst family members whose loved one has received MAiD, that I analyzed the findings of this study.

In keeping with this method of analysis, findings will be presented following the musical style of a fugue, as described in the next section. The chapter moves through the following sections (and themes). First, a *prelude* provides background to each of the seven participants. Second, the *exposition* includes a description of the *subject*, which highlights the relationship participants have to themselves, and a description of the *countersubject*, which moves alongside the subject and describes participants' relationship with their loved one who received MAiD. In the exposition, the four *voices* that the subject and countersubject move through are also introduced. Following this, the chapter moves through the *development,* which contains *episodes* exploring the participants' relationship to other external people and structures. After listening to the

movement of these relationships to self, loved one, and other, the *recapitulation* and *coda* provides insights for healthcare providers from family members whose loved one has received MAiD. By using the style and form of a fugue to structure the findings, the complexity of family members' experience are honoured.

Composing a Fugue

A fugue offers a complex structure for distinct, yet related parts to move together in a coherent musical composition. In order to better appreciate the rich findings, a brief overview of the structure and components of a fugue is provided. In the late Baroque period (1685-1750), composers such as J.S. Bach, K. P. E. Bach, Telemann, Vivaldi, Scarlatti and Handel utilized harmony, counterpoint, and polyphony to create music unique to this time period. Baroque composers were "expected to move the affections of [their] audience" (Gauldin, 1988, p. 2). The texture of baroque music is contrapuntal, and the compositional structure is determined by tonal centres, as opposed to thematic contrast, as seen in later works (Gauldin, 1988). Modulation is frequently used in Baroque music, offering contrast through the shift of tonal center (Gauldin, 1988). Motivic manipulation is also used, in which melodic fragments "undergo extensive subsequent development" (Gauldin, 1988, p. 26). This structure, contrast, and ongoing development of modulating melodic fragments or motifs provides a helpful metaphor to appreciate this study's findings.

Counterpoint, a term "derived from the Latin *punctus contra punctum*", translates as "note against note" (Gauldin, 1988, p. 33). Gauldin (1988) emphasized four characteristics of Baroque polyphony, or the interplay between the various voices in a contrapuntal texture: (a) the composite melodic notion generated by separate parts, (b)

rhythmic interaction between these parts, (c) the registral placement of voices in relation to one another, and (d) the resultant consonance or dissonance and the sense of harmonic progression. Voices may move in the same direction, in contrary motion or opposite directions to each other, or in oblique motion, in which one part is sustained while the other part or parts move (Gauldin, 1988). With distinct voices moving at a different times, Gauldin described how this contrapuntal motion of voices, "accentuates their independence and gives a pleasing interplay among them" (p. 149). Rests are used strategically in each voice to give a sense of "breathing" and a clear-cut delineation of the separate segments of the music (Kennan, 1972, p. 229). Though debated as an actual musical form, or simply a style, fugal writing can be described as "a *way of writing,* a particular contrapuntal approach" (Kennan, 1972, p. 200).

Fugues generally contain three key parts: (a) an exposition,(b) a development section, and finally (c) a recapitulation. In the exposition, the subject is introduced in the tonic key as a short line or "question" that is interesting and readily recognizable in melody or rhythm. After the subject is stated alone, a second voice enters (the countersubject), stating the subject in the dominant key, providing the "answer." A *countersubject* is defined as a:

> melodic idea that appears consistently along with the subject in the exposition-from the second announcement . . . it must also have melodic interest, individuality, and enough rhythmic contrast to make it a good foil for the subject, yet the two must make a satisfying combination. (Kennan, 1972, p. 205)

Regarding the relationship between the subject and countersubject, Oldroyd (1948) summarized, "The two must *belong to each other"* (as cited in Kennan, 1972, p. 205).

In a fugue, the subject and countersubject move together through a determined number of voices, typically three or four. Kennan (1972) noted that:

> at least one of the voices in a four-voice contrapuntal fabric is likely to be somewhat subordinate in importance at any given point, since the ear would have difficulty in following four lines of equal significance and complexity for any extended period. The music is most often constructed in such a way that the listener's attention is focused first on one line, with its supporting counterpoints, then on another such combination. In most four-voice contrapuntal works, all four voices are not involved continuously. (p. 207)

This carefully constructed "contrapuntal fabric" that directs listeners to hear significance, complexity, and even absence of voice resonates with the previously stated goals of the LG to "listen for nuance, modulations, and silence" (Gilligan, 2015, p. 72). The development section follows the exposition, using episodes that draw on material from the subject and countersubject, to smoothly transition, or modulate, from one key to another. The recapitulation marks the final section of the fugue, and it often contains a coda, which "presents a final, harmonized version of the subject" (Kennan, 1972, p. 223).

This understanding of contrapuntal music, specifically the form and style of a fugue, helps readers hear the multiplicity of voices expressed in the data. Following the steps outlined in the LG, the transcripts were analyzed to hear the various voices held by individuals. After listening for these voices in each individual transcript, four broader voices emerged to capture the wider range of experiences represented among participants as a whole. The individual voices of participants, as well as these four broader voices will be presented as a fugue following a prelude that offers necessary context for each participant.

A Prelude: Providing Context and Listening for Plots

In baroque music, a fugue is often prefaced by a comparatively short piece of music called a prelude, which introduces rhythmic or melodic themes or motifs. Before introducing the subject and countersubject in the fugue (i.e., my presentation of the

research findings), it is important to provide some introduction of underlying contextual factors significant to the stories of family members whose loved received MAiD. The first step in the LG is *listening for plots*. A brief description of each participant provides an overview of several key aspects of each participants' story, all of which will inform the various sections of the fugue. It is worth noting that with my analysis, I did not seek to isolate that which was unique to participants' experiences as a direct result of MAiD. Aspects of their stories may overlap significantly with experiences of family members whose loved one experienced an unassisted death. I have aimed to portray these stories in their fullness, as they were conveyed to me.

"Jeoffrey"

Jeoffrey and his wife met later in life and had plans to work hard and then enjoy retirement together. This plan was interrupted with her diagnosis of ovarian cancer. For two and half years he cared for her, and he rested in the fact that "I know, in my heart of hearts, I did the best; I know these neighbours and friends of mind, they constantly still tell me, to this day, 'Jeoffrey, you went above and beyond.' But, to me, it's like, 'What else would you do?'" He recalled the challenges of being her caregiver, in light of his "fix- it" personality. He said:

> I had to accept that [there is no right answer], which, for me, is difficult because . . . I come from a mechanical, handy background . . . once I start [to fix something], I want to finish it and I accept the challenge; I'm not going to sleep at night until I know I've solved it, fixed it.' But I had to learn that this one I can't fix, right?

Jeoffrey and his wife were "straight, upfront people" who "asked good, solid questions, and [the doctors] could be very forthright with their answers." Together, they tried to accept what he calls "their new life" with its restrictions, and "make the best of it." He

described how during those two and half years he made no plans. He tried to take care of his wife financially, emotionally, and physically. For example, he described how he bought her an e-bike, so she could maintain some independence, and how he gradually took over the cleaning, the cooking, and reluctantly, her physical care.

Jeoffrey remembered feeling hopeful while his wife was still receiving treatments. This hope dwindled as he watched her decline physically. He administered her medications, and he did his best to keep the promise he had made to her and her family to care for her at home as long as possible. As she got weaker, they decided together that it was time for her to move to hospice. Jeoffrey described how this transition required him to surrender the sense of control he still felt he had. The hospice chaplain was the one who made his wife was made aware of the option for MAiD.

Jeoffrey was supportive of his wife's decision to have MAiD. Along with offering a means to end her suffering, choosing MAiD allowed Jeoffrey and his wife to regain a sense of control. For example, in making arrangements for MAiD, Jeoffrey was able to notify family who needed to travel for the chosen date and time. He described other benefits of MAiD, including the opportunity to plan the funeral ahead of time, when decisions related to the program and cost of the funeral could be made more clearly, with what he described as less clouding of emotion and more explicit integration his wife's preferences.

On the day of his wife's death, Jeoffrey's friend came to help him clean up her room at hospice. From hospice he went home and contemplated what to wear to an occasion such as this. His wife's family had decided to go for a final dinner together in the city near the hotel where she would receive MAiD. He described vividly how difficult

those hours were for him. As he brought her to the building, he told of his distressing realization that he would be bringing an empty wheelchair down the elevator with him in a few short moments. After some final words, Jeoffrey's wife received MAiD in the presence of her husband and her siblings, and the palliative doctor from hospice, who had come to observe MAiD for the first time.

"Tabitha"

Tabitha and her husband knew each other for 12 years and were married for eight. They both had children from previous marriages, and she described their relationship as "pretty storybook material." Her husband was diagnosed with a terminal cancer four and half years prior, and together they shared the financial, emotional, and physical burden of receiving treatments including alternative medicine, chemotherapy, and radiation. Her husband's ex-wife (a family friend and the mother of his sons) had died just prior to his diagnosis, and this added pain to everyone involved, especially his sons. In addition to cancer, her husband suffered from depression, and she noted that "we never knew if we were dealing with signs and symptoms of cancer or signs and symptoms of depression and anxiety . . . I think, at the end of the day, it was the depression that got him."

Tabitha referred to their illness journey, saying, "we were playing whack-a-mole; it was terrible . . . we'd just get one thing cleared up, and there was something else; he was in and out of the hospital at least twenty times." She quit work to take care of him, and she described feeling "burnt-out." After months of trying to care for him, Tabitha's husband was transferred to hospice to receive respite care. It was here that he said to her, "I'm done. I'm done."

It was Tabitha who first heard about MAiD and proposed it as an option to her husband. After consulting with several doctors and being accepted for MAiD, they waited several months to proceed. While Tabitha was away, her husband made his final decision to choose MAiD. Tabitha described what she experienced as a disconnection with her husband after he decided. She described how she kept begging him, "Please, please, please share with the boys (his sons) what is happening." Several days after telling them, her husband received MAiD at the hospice. His sons and their wives, her husband's sister and her partner, Tabitha, and her sister were present. Thinking back, Tabitha rested in the fact that he made his decision independently. She found comfort in the sense of certainty he conveyed his decision with, noting that "he wasn't nervous or anything."

Tabitha was grateful her husband died peacefully and could have a hand in planning his own final days. In a comparative reflection, she noted that she had seen her mother pass naturally and that that too was peaceful. She was grateful for the opportunity for final conversations that her husband's choice for MAiD created, and she emphasized the courage her husband showed in choosing MAiD. She spoke of her admiration of his decision, describing his actions as noble.

While Tabitha benefited from the care of the chaplain while her husband was in hospice, she struggled emotionally after her husband's death, finding it difficult to return to work. Even when she reached out for bereavement supports, no aftercare was made available to her. Throughout her story, Tabitha was a caregiver to her husband and a protector of her husband and their children. She acted as an advocate for her husband's needs, and she defended their close relationship.

"Landon"

Landon and his wife knew each other for about 44 years. They had a close relationship, as Landon explained, "we were very, very tight. We did everything together; we didn't have a lot of friends or family, so it was us all the time. We never did anything without each other." In 2011, his wife was diagnosed with Chronic Obstructive Pulmonary Disease. He watched her—his previously independent, active wife—lose more and more of her independence. He described his sense of helplessness, and his struggle to care for her as she developed chronic pain and a sense of embarrassment with her physical decline. As she began to discuss MAiD as an option, Landon's proximity to her pain and struggle led to a shift in his values. He recalled, "She didn't want to be in the world if she didn't have any quality of life." He recognized that prior to this unique situation he would not have supported MAiD. As he witnessed his wife decline, however, he described having a "complete reversal of thought."

Landon reflected on his desire to help her pursue MAiD, and he described his desire to hold on to her as "selfish." When reflecting on his involvement prior to her death, he explained his felt sense of duty and responsibility to not interfere with the process and procedures surrounding MAiD, but to follow along as directed and corroborate "everything that [she] had to say." He explained how she planned the event, choosing the first available date, and making funeral arrangements noting, "She always made sure all the loose ends were tied, even until the bitter end." She died peacefully, with Landon and her son on either side of her.

The hardest part about MAiD for Landon was the finality it brought. When reflecting on what it felt like when his wife was "approved" for MAiD, he said, "She and

I high-fived each other, actually, because even though it was the worst of times, it was also the best of times. We were very, very happy; she was so happy afterwards." The relief of suffering and the promise of dignity that it provided his wife made him describe MAiD as "meaningful."

Through his story, Landon was a caregiver and companion to his wife. He continued to honour his wife through his ongoing task of remembering. Landon trusted his memory, but he described feeling subject to it and the way it affected him, even months after his wife's death. He noted that, "I got a very good memory; sometimes, I've got too good of a memory." Remembering became his burden to carry. By telling her story, Landon took comfort in the fact that "her story is going to remain alive."

"Deborah"

Deborah and her husband met in their late forties and were married for 20 years. She spoke with great admiration for his wisdom, his knowledge, and his wide range of interests including astronomy, travelling, philosophy, and history. After months of feeling ill, Deborah's husband was diagnosed with cardiac amyloidosis. She described his deteriorating health and the lack of control they both felt. She remembered struggling with hope, recognizing her attempts to slow down his illness by getting him to the cottage were out of "false hope" in retrospect.

Recalling his physical deterioration Deborah explained, "He did not want to live that way. He wanted to engage and be part of things. He did not want to live just for the sake of living." When describing her own experience, she used the phrase "double 'got-you'" to explain her felt tension: A part of her trusted that MAiD was the best decision for her husband; a part of her resisted the finality of his decision.

Close to one year after his initial diagnosis, Deborah's husband received MAiD at home. Deborah took comfort in the fact that by the time her husband received MAiD, he was near natural death. The doctor and nurse practitioner involved said, "We have only shortened his life by probably a day or two." She stated, "He would have died anyway—which is immaterial, I think, to the whole issue, because he still chose it." The fact that his choice was honoured made the process around his death "calming."

Deborah was a caregiver for her husband until the end and a presence for him—sitting with him, reading the paper, talking with him, or giving him something to eat or drink. She reflected, "[MAiD] just seemed to be natural; like, it just seemed to be the way that things should be, 'This is what you're planning; this is what you want and . . . ' you know, 'we'll live it as much as we can up to that moment. But we know that you can't do anything more, so that will be the end of it.'" She continued to think about him, noting that remembering him, reliving their trips and conversations, and telling his story "kind of brings him closer"; "As long as I have my memory, then I've still got him here."

"David"

David and his wife were just a few days away from their 50th wedding anniversary when she received MAiD in their home, with friends and family members present. David emphasized the importance of clear and open communication regarding not only the availability of MAiD and processes surrounding it, but of palliative care, or "comfort care," itself. He recalled the relief his wife and he experienced when her doctors finally acknowledged that she was in fact, dying. With major cardiac concerns, David's wife was in the hospital for three weeks prior to returning home with palliative care. He

stated, "In palliative care, I had complete help, you know. But, up until then, I was carrying it myself; that was about two or three years."

Having time to accept the fact she was dying, and her decision to receive MAiD, allowed for David and his family to have a sense of agency and control around the timing. Though she was approved for MAiD, David's wife decided to postpone the procedure and receive palliative care at home until she could not manage the symptoms. After nine months at home, she decided it was time. Together David and his wife carefully planned the details of who would be present and how the final days and moments would unfold. He denied feeling rushed and believed her ability to plan all the details of her death made it feel like it was her own.

For David, accepting [MAiD] was "a process; it's not an event; it's not a surprise; it's a sort of gradual process." He explained how his wife:

> knew her body and she knew what was going on—and she had, of course, consulted with me, we were on the same page. But the family—our two boys and their wives and our grandchildren and everybody—had to get onside bit by bit, you know.

Recalling their mutual "acceptance of death as a part of life," he found comfort in some of her final words: "Look for beauty in all things, and expect love at all times, and be grateful for life itself." She used to say, "We can't be greedy, David, we've got five granddaughters and two lovely sons and their wives. And we have great-grandchildren. You know we've had a wonderful life and we know that part of life is death." For David and his wife, MAiD provided "a chance to end life's process" and "allowed us to be together till the end; it allowed [wife] to be herself to the very end of this life, and it allowed us to say together all the things we wanted to say together."

Grateful for his families' willingness to help and their acceptance of her decision, David hoped that medicine itself will shift to where it acknowledges death as a part of life. He believed, "palliative care is a model for medicine tomorrow, in my mind . . . Offering the service of medically-assisted dying accepts . . . the fact that people die. And once you do that, you will revolutionize the way medicine is offered."

"Sandra"

Sandra and her husband spent forty-four years together, and she began her reflection of their relationship saying, "It was a classic doctor and nurse [story]." Him a surgeon, and her a registered nurse, they together raised five children. In 2007, Sandra's husband had quadruple bypass surgery and struggled to recover. Fifteen months later he had a stroke. After moving to a senior's apartment, they discovered that he had Parkinson's disease. She explained that their combined knowledge and experience as healthcare providers meant that "we both knew enough about Parkinson's disease that he wasn't going to get better; he was going to get worse." He experienced a "fairly fast progression of the disease" and Sandra became the primary caregiver.

Feeling trapped, Sandra's husband was prepared to end his own life. That is, until they heard a radio program on CBC about MAiD. Sandra explained:

> I'd always known that [he] had said he didn't want to live with a chronic disease, and he wouldn't live with a chronic disease . . . I think [that radio program] indicated to him that that was a possibility that might have more dignity than a suicide in the family home.

For her husband, knowing there was a way to end his suffering made the Parkinson's more bearable.

As his caregiver, Sandra "spent all day pretty nearly every day with him". She described the process of caregiving, planning, and advocating as an exhausting process,

noting that, "there's . . . not a lot of space for self when you're supporting someone on that journey. I mean there's not the emotional space, there's not the time, there's not the headspace," Sandra also recalled the added burden of the application process, describing the pressure she felt to prove how her husband met the criteria. After finally receiving confirmation of his eligibility for MAiD, the site manager at the nursing home provided support in planning the details, and the physician made himself available for questions at all hours. Knowing he was eligible brought great relief.

Sandra's husband received MAiD in his room at the nursing home, with Sandra, the family doctor, one nurse, and the site manager present. Their children were down the hall in the family room waiting until after the procedure. Looking back on the challenging process, Sandra explained, "it was a peaceful and dignified death in a room that was filled with love and respect. And it was just the way I think most of what would like to die."

Though they maintained secrecy throughout his decision-making process and after his death, Sandra was now telling his story and advocating for MAiD as a positive alternative to "lonely, silent suicide." She wondered if her grief narrative was different than those whose spouse had an unassisted death, and she hoped that "as [MAiD] becomes a more common procedure, that everything about it will stop being its own little world." She hoped that soon loved ones would not feel the need to be silent, and she advocated for increased awareness around the availability of MAiD, increased access to palliative care, as well as decreased barriers for patients applying for MAiD.

"Megan"

Megan's father received MAiD just seven weeks after being diagnosed with cancer. He died in a room set-up for MAiD in a local nursing home, surrounded by his

wife, and all of his children except for one. She described many complex relationships in her family. From diagnosis through the time of her father's death, Megan tried to protect her family as a whole, particularly looking out for her mother. She took an active caregiving role in driving her parents to her father's appointments, and she tried to help her siblings understand and come to terms with their father's decision to receive MAiD in light of their religious and personal values. She described herself as having to be "super-logical" and "a consoler," and she identified as a placator, a mediator, and a caretaker.

When telling her story, Megan explained, "I often give more backstory than is required." She saw the complex relational dynamics impacting her own experience of MAiD, as well as that of the rest of her family. Megan struggled with her dad's decision, as she saw his effort to fight for control and fight to protect his public image. She described knowing the date and the time of "death day," as she referred to it, to be "psychologically torturing" to both her mom and herself, especially in light of the relational conflict throughout the family. Her own experience of "death day" was spent caretaking other people.

Recalling the events of her father's death, Megan described the confusion and uncertainty in the room as her family sorted out various details including who would hold which hand, who would sit where, and who would say what. The entire process was interrupted several times by a nurse coming into the room unaware of what was happening. The confusion was confounded when the injections were administered prior to the family being made aware that their father or husband would now be taking his final breaths. All of these situational factors, in addition to the relational issues and traumatic

memories of the past, meant that for Megan, her father's death was very painful. It was complicated further by the processes surrounding MAiD.

As her family grieved, she explained that as a result of complex family dynamics, her family continued to experience the effects and ramifications of his decision for MAiD. Since then, she watched some members of her family become isolated, noting that for her Mom, "her circle of friends is getting pruned a little bit by people who judge her for having allowed this to happen, which is weird because Mom didn't want it to happen." She lamented her own experience, wishing she had been more aware of her own needs throughout her father's dying process.

After her father's diagnosis, Megan met with a counsellor. She said, "I'm trying really hard to just live my life without reference to what everybody else needs. But, when they come with a need, I'll try to meet it; but it's a little different now, I guess." In regards to her relationship with her father, she reflected:

> I think I'm still saying goodbye; because I'm doing a lot of work on just allowing myself to be angry and to say, "Okay, I can love someone, and also be really, really mad at them." Because, my whole life, I have not really let myself be angry at people. It's like, that was the big sin, you know; so I'm still saying goodbye, I guess.

These seven stories represent the beginning work of the listening guide, which involves listening for main plots in participants' narratives.

Seven Participants, Seven Mini-fugues

By providing this introduction for each participant, readers can better appreciate the context and underlying plots unique to each story. Listening for these plots, as the LG suggests, draws "attention to the landscape of the interview or text" (Gilligan, 2015, p. 71). In keeping with the musical metaphor of a prelude and subsequent fugue, the

background provided in this section introduces the underlying motifs that will be further developed as findings are unpacked in the fugue. After listening for the plots (described as the prelude), the following sections of the fugue draw on the other steps of the LG, with these findings presented as my *composed analysis* (step 4 of the LG). Prior to exploring the overall subject, countersubject, and various voices reflected in the data at large, it is necessary to emphasize that each participant holds and expresses their own array of voices. As Gilligan et al. (2003) explained, the voices of an individual may at times appear to be incongruent, contradictory, running parallel, or ranging in degree of volume or presence. Sorsoli and Tolman (2010) explain that, "every person's voice contains multiple melodic lines" (p. 498). In this sense, each participant's experience could be described as its own mini-fugue. Before looking across the data amongst participants, individual transcripts were listened to and analyzed for these contrapuntal voices. A selected representation of voices heard is shown in Table 2. While not a comprehensive list of all voices present, it is clear in seeing this list of voices that these participants' experiences are complex; each individual's fugue is made of up of unique voices, and each individual has more than one voice. Through listening for the voices present in each individual's distinct mini-fugue, I was able to look across the data to identify and explore the study's broader findings, examining how the voices across participants move together through the fugue described below.

Table 2

Voices heard in individual participants

The caregiver voice	The "fixer"	The realist
The protector	The defender	The advocate
The voice of exhaustion	The "we" voice	The voice of admiration
The voice that honours the plight	The voice of experience	The invisible, "do I matter?" voice
The voice of self-compassion	The helpless observer	The voice of insecurity
The voice of agency	The active storyteller	The voice of acceptance
The voice of gratitude	The voice of letting go	The voice of relief
The voice of certainty	The determined voice	The voice of shame
The second-guessing voice	Voice of gatekeeper	The confident voice of authority
Voice seeking control		

Presenting the Fugue: MAiD and the Multiplicity of Family Members' Voices

In the presentation of synthesized findings that follows, I explore the relationship participants have toward themselves (presented as the subject) and their relationship with their loved one who received MAiD (presented as the countersubject). In the exposition, these relationships move together through four dominant voices of witnessing, caregiving, honouring choice and supporting dignity, and surrendering and letting go. This is followed with the development, where four episodes describe how external relationships and factors impact the experience of family members. These episodes explore how one's role in their family, one's relationship with the healthcare team, one's experience of support and accompaniment from friends, and one's experience of stigma, secrecy, and isolation may influence their experience of MAiD. The final aspect of the analysis (recapitulation and coda) focuses on what participants described as helpful and

less helpful. Overall, the findings illuminate MAiD as a unique experience for family members.

Exposition

As described above, in a fugue, the subject and countersubject move together through the various sections. In these findings, the subject and countersubject, or these relationships to self and loved one, are experienced differently for each participant. Though the LG explicitly listens for the "I" voice in each participant's story, in this particular study, listening for the "we" voice of the family member and loved one also took on importance. The "I" and "we" voices, or parts, are difficult to separate and often overlap, with participants at times shifting between voices in the same sentence. This attention to how participants view the "I" and the "we" becomes significant in appreciating the interplay between the subject and countersubject throughout the fugue.

Subject: Relationship to self. When reflecting on their experience of MAiD, each participant described in varying degrees how they themselves felt a part of or integrated into the decisions, planning, and procedures surrounding MAiD. Some participants described themselves as being very involved and interwoven with much of the MAiD process for their loved one. Their reflections indicate that they were very much "on board" with the decision to pursue MAiD and that they felt that their involvement and actions related to MAiD were congruent with their values and beliefs. Others described feeling tension between what they thought would be best for their loved one and what they felt or would hope for in the given situation. Some felt they had to silence their doubts, their emotions, or their different perspectives in order to honour those of their loved one. Still others described feeling that the processes surrounding MAiD were

centered entirely on their loved one and that there was no room for their own experience to be factored in to the decisions made. This lack of space was grieved by some and accepted or even welcomed by others, likely due to the fact that their loved one was the one experiencing such a high degree of physical suffering. In order to explicitly listen for this relationship to self, I created I-poems for each participant, emphasizing the subconscious voice of the participant. Quotations and I-poems will be used to show three distinct, yet related aspects to integrating the self as seen in the data: suspending the self, negotiating room for the self, feeling tension within the self.

Suspending the self. One way participants described their relationship to self can be understood as a suspension, or even a detachment, of their self or a part of themselves. This was seen at times as a conscious suspension, with the participant willingly giving up a part of themselves for the greater good. In contrast, some participants described this suspension of self as a subconscious action, in which they were unaware of how they had suspended themselves until after the fact. Several participants described feeling that it was their duty or responsibility to give up any reluctance or hesitancy they felt in regards to their loved one's decision to receive MAiD. Acknowledging their own objections, reluctance, or even needs was seen by some to be "selfish." For some, they also describe a suspension of personal beliefs or values.

Landon described the way he suspended his own beliefs and even his own desire to have his wife live longer. He described coming to a place where he could fully support his wife's wishes. This happened over time, as a result of watching her suffer. He explained:

> I know, many years ago – many, many years ago – I would have never supported those thoughts. But, as it hit closer to home, I had a complete reversal of thought

> and, you know, I fully supported her wishes. And, you know, and who can argue with her plight?

Landon described his state of helplessness and spoke about how "letting her go" was his way of "becoming unselfish." He continued:

> I was fully supportive, actually. I was: 'If there's anything I can do to help, just please let me know,' because I didn't want to see her like this. And, even though I loved her with all my heart, I couldn't stand her being like this. I actually had to let her go; I had to become unselfish, and I just had to let her go.

In these statements it seems that Landon felt a willingness, alongside a sense of duty, to suspend his previously held beliefs in order to become more congruent with his evolving values of prioritizing his wife's personhood or sense of self over his own. This suspension of himself occurs overtime and as a result of watching his wife's health decline. With this suspension of himself, there is also an honouring of himself and his redefined values noted in these statements.

This suspension of the self looked slightly different for Deborah, who admitted that she did not feel part of the MAiD process. She clarified, however, that she was happy that the focus was entirely on her husband. She explained:

> No, I didn't feel like I was part of it; I felt like the attention was on [my husband]; but I wanted it to be on [him], too. Like, I didn't want to be part of that. I thought, "Well, I can look after myself when this is over." You know, like, not that I didn't need them, but I felt like their focus had to be [name] at that time. I don't remember anybody asking me anything, or saying, "Is this what you wanted?" Or, "Is this what you want?" I don't remember; that doesn't mean that nobody did; I just can't remember. I guess because it wasn't important to me at the time; you know, I felt like he was the centre; he had to be cared for, and he had to . . . his wishes had to be respected, not mine. And if I had said, "Yeah, yeah, I want him to have MAiD," or, "No, no, I don't want him to have MAiD," I didn't think that should make a difference. Because it should be what he wanted . . . it was very focused on him.

Her statements seem to suggest that Deborah felt there was a limited amount of care or focus that can be provided during MAiD, and she felt that the patient should be the

recipient of all care and attention. She was willing to forego care for herself if it meant that her husband could be well cared-for. If her loved one was at the centre of care, she could not be.

Deborah also responded to the questions of "did you feel cared-for in the process? Did you feel that your values were welcome" by noting that having her values welcomed would mean that she was asked if this was what she wanted. This represents a narrower understanding of what integrating a loved one's values might look like. Though her beliefs and values seemed to align with those of her husband, she felt that MAiD should not be about family members, and she suggested that if her values or beliefs were different than her husband's she would and should willingly suspend these for the sake of honouring his decision. In both of these cases, the suspension of self was done willingly. Emphasis was placed on the prioritized needs of the loved one.

Some participants described moving closer to their loved one physically and emotionally in the time leading up to their loved one's death. With this increased sense of closeness to family members and significant involvement in planning the events surrounding MAiD, some participants noted that when looking back they see how they actually disconnected from their own feelings or needs. One participant described focusing on caring for her husband, trusting that she could look after herself "later." Even when family members described being close to their loved one relationally, or being close to their loved one physically in terms of spending time together and providing care, participants did not necessarily feel that who they are as a person or what they needed at the time was integrated into the processes and procedures surrounding MAiD.

Megan described physically and emotionally moving in closer to her family in the time leading up to her father's death. She became very involved in the tasks and busyness of preparing for MAiD, though her own personhood—including her values and beliefs—was very much excluded from decisions and the event itself. Until after her father's death, Megan was largely unaware of how much she had suspended or even detached from herself throughout the events surrounding her father's death. Her growing awareness of this detachment is shown in the following I-poem. The I-poem also reveals how the complexities of family relations are amplified in the context of MAiD.

Taking One for the Team

I was a placator
I was always making sure that his stuff was taken care of
I just sort of made sure he was not angry so that he wouldn't hurt other people
I took Dad to appointments
I had to be super-logical
I felt like . . . well, that's been my role
I was always told I was the peacemaker or the harmonizer, smother-over of things
I cancelled all my teaching for that semester because . . . . I didn't see how we were going to get through it otherwise
I don't have kids
I honestly do get a sense of accomplishment out of meeting crises head-on
I think, because of lots of precedent being set that way, my voice doesn't matter in my family very much
If I speak up, I'm slapped down right away
I don't matter
I was like, "Well, I mean I kind of get it"
I mean I certainly get not wanting to suffer
I don't know how painful it was
I don't know if I could take it
I'm a consoler
I was consoling him [my brother]
I was consoling Dad about how [my brother] couldn't get it
I went to all those appointment too
I just remember Mom reaching out at one point trembling and holding my hand
I think it was almost harder on my Mom
I think just all the prep for it was just torture because it was like . . . yeah, it was the anticipation part

I went over to their house to help with something—I forget what—but Mom had gone grocery shopping
I suddenly yelled at him
I said to him, "You need to . . . you need to think, not just about the image you're leaving behind for the public, but leave Mom with some tenderness"
I'm not God, so I'm not going to judge him—but I do, honestly
I think we're all hypocrite on some level
I can always see both sides
I can always make excuses . . . I can be like, "Oh, well, they did that because they're reacting to this," and you know . . .
I just go, "Maybe I should be compassionate towards myself today . . . and just not let people have excuses" you know?
I actually suggested, when the pastor said he wouldn't come, I said, "Mom, why don't you ask Uncle [name], because they're pretty close?"
I took one for the team and had her stay at our house
When I say that, I mean because she's a very difficult person
I was like, "I feel nothing"
I just felt like, "No, he's just disappeared"
I was just caretaking other people that day for sure

After much reflection, Megan had come to a place where she saw how she could have brought more of herself into her experience of MAiD. She explained, "I wish I'd been a little bit more selfish. I wish I'd asked for more of what I needed at the time. But I also get how I didn't feel I could." By calling this care of self "selfish," Megan seemed to connote a negative moral judgement on the idea of prioritizing care of self. However, throughout her story, she translated her understanding of "selfish" into a more positive term that allowed for care of self and care of loved one. She regretted not honouring herself more when she said:

> I'm trying to find a balance between not placating . . . like, I regret my role at my Dad's funeral, actually; I regret standing up there and eulogizing him, and saying what I did – not because it wasn't true, but because . . . just because it felt . . . it sort of . . . it was damaging to myself. It was damaging to be up there and keep perpetuating, like, at the expense of my own story . . . Because it sort of splits you into two people, and, you know, it's jagged.

As Megan reflected on her involvement in her father's death, she continued to try to

integrate her own personhood into her memory. When telling her story, she expressed moments of detachment from the event itself, working through the disintegration of self that she now identified in her story. Through these participants, we see how several family members felt, whether consciously or subconsciously, the need to suspend themselves for the sake of their loved one and to meet the situation's demands.

Room for self. One of the factors impacting the integration of self into the MAiD experience for family members was the space—emotionally, physically, and mentally—created or not created when their loved ones were preparing to receive MAiD. Pressures on time were also felt by participants. All of the participants described their role in caregiving for their loved one and other family members, and this seemed to impact the degree to which they could integrate themselves into the MAiD experience. Participants described feeling a lack of space for themselves while caregiving, though they did not all place the same value on this space for self.

For Sandra, there was not much space for herself as she cared for her husband. The following I-poem speaks of how her role as caregiver left her "pre-occupied." Her care for her husband filled what she suggests is a limited space that could otherwise have been occupied with care for herself.

Space for Me

I was the primary caregiver
I don't know
I think it was about three years before I started getting someone
to come in when I went out because he was falling and he couldn't get up by himself
I just hated coming home and finding him on the floor
I've seen lots of death as a nurse and even in my family
I've been with several family members when they've died
I think [you] just go back and forth, "Nothing can be worse than what he's going through now, except what he's going to have to go through tomorrow, and that would be an escape"

I mean there's not the emotional space, there's not the time, there's not the headspace
I think it was good in a way that I was so preoccupied
I could sort of . . .
I could listen to him and agree with him, but not have much time to think about
I spent all day pretty nearly every day with him
I didn't know what to think
I didn't know what to think
I decided not to call [him]
I would wait till the next morning and tell him in person
I didn't really know how I should feel
I mean I could be happy that this was the news he'd be waiting for, but, on the other hand, my husband was going to die in five days
I was there for almost all of it
I was there just because I was always there

The effects of this limited room for self can heard in multiple participants in the voice described later as "caregiving." It is seen here in Sandra's case that the forced preoccupation with care and meeting her husband's needs was in some ways a welcomed distraction. The limited room for self was not a conscious decision or something Sandra overtly consented to; rather, it was a natural consequence of her husband's increased needs, her role and desire to support and care, lack of other caregiving supports, and the nature of their relationship. The room for self, or lack thereof, impacted how much Sandra could take up space in her husband's dying process.

Feeling the tension. Several participants described tension within themselves, feeling a pull between honouring their loved one's request and decision for MAiD and experiencing their own sense of doubt and dread with that reality. There was also tension noted by participants in listening to one's rational self versus attuning to one's emotional self. Holding these tensions, participants described what brought relief to the agonizing back and forth.

Deborah described her felt tension when she said:

> I mean it's kind of a double . . . I don't know, I was going to say a double "got-you", but that's not even the right term. It's kind of . . . it seems double-edged. You know, there's a part of you that says, "Yes, this person needs this because he wants it, and he doesn't want to live this way." But there's another part that says, like, "This is so final." Like, "This is it." Like, "You make this decision and it's over; it's done." Like, "There's no turning back." Well I mean there is turning back until the moment of; but once it's done, it's done. Like, once they've injected you, it's finished. So you really have to know. Like, he really had to be convinced that that's what he wanted – and he was. I mean there were moments of doubt I had, and I thought, "Oh, God, do we really want this? Does he really want to do it this way?" But I mean that's emotional response. Really, I knew that there was no way his life was going to get any better; it was just going to continue to deteriorate until he probably couldn't sign anything, or even think, or see, or take in anything . . . but it is kind of cold comfort to know that he died with cognition. Like, he knew I was there; he saw me in his face; he felt my hand; I mean he just . . . he knew I was there, and that part is reassuring in some small way. Whereas I think, if . . . you know, if the person is dying, and they're unconscious or they've completely lost cognition, they don't know who you are . . . I can't imagine that that's very satisfying.

Here Deborah's rational understanding, where she "knew" the certain outcome of her husband's illness, was in tension with her emotional experience, where she felt uncertainty and feared the finality of his decision. Deborah described these "parts of you" as countering each other in this complex, no-win situation. She took comfort in her decision to follow her own cognitive senses, focusing on the cognition her husband was able to hold onto as a result of choosing MAiD.

Sandra also described feeling strong tensions within herself, describing parts of her body that feel different from one another. She explained:

> Well, with one side of your face, with one-half of your heart and your being, you're providing physical and emotional care and the necessities of daily living; and with the other half, you're listening and sort of agreeing that, "This may be the best option that he has." It tears you apart; it tore me apart; it was very difficult . . . So you, I think, just go back and forth, "Nothing can be worse than what he's going through now, except what he's going to have to go through tomorrow, and that would be an escape."

The "back and forth" process was difficult for Sandra and in itself took energy and determination.

Sandra went on to describe how the relief she saw in her husband offered some solace in the midst of the tension she was feeling. After getting the news from the physician that her husband was indeed eligible to receive MAiD, she described her uncertainty in terms of thoughts and feelings:

> So I didn't . . . know what to think; I decided not to call [my husband]; I would wait till the next morning and tell him in person. So I didn't really know how I should feel. I mean I could be happy that this was the news he'd been waiting for, but, on the other hand, my husband was going to die in five days . . . But when I told him the next morning, he was just so happy; he was just so relieved. He was just beaming in a face that couldn't smile anymore, you know, just for a moment. He was just so very, very pleased to think that he wouldn't have to wait that many more mornings.

Her husband's response, which carried with it such certainty, brought Sandra a degree of comfort in the midst of her uncertainty. Across the participants, tensions carried, especially in the time leading up to their loved one receiving MAiD, impacted how they felt their personhood or these at times seemingly contradictory parts of themselves were integrated into the overall experience.

To summarize the subject, which runs throughout the fugue, participants describe varying experiences of how they see themselves—their unique personhood—as being welcomed or not welcomed into the processes and procedures surrounding their loved one receiving MAiD. Their integration of self, and their relationship to their self throughout the entire process leading up to, during, and after their loved one's death varies in degree. This subject, relationship to self, sees participants suspending the self, negotiating room for the self, and feeling tension within the self. As participants express their "I" voice, describing how and where they see themselves integrated into the

processes and procedures surrounding MAiD, the "we" voice, which moves concurrently with the "I" voice, must also be acknowledged. The countersubject, relationship to loved one, also impacted the experience of family members whose loved one has received MAiD.

Countersubject: Relationship to loved one. In the fugue, the subject (in these findings representing participants' relationship to self) runs alongside the countersubject, relationship to the participants' loved one. Participants referred to their relationship with their loved one using a variety of descriptors from "unhealthy" relationships to those of great admiration. Many participants described a felt sense of togetherness throughout the entire process of MAiD. For some, decision-making was seen as the task of the person receiving MAiD; others saw this as a joint task. Several participants described how given the circumstances leading to MAiD, the sacrifice of their own preferences, needs, or beliefs, was willingly made, suggesting that the "we" voice, or in some cases the "they" voice, supersedes their own "I" voice. In order to explicitly listen for this relationship between the participant and their loved one, the significance of regard for and connection with the loved one will be considered, as well as how involvement in decision-making may impact the experience of MAiD for family members.

Regard and Connection. Many participants told of the respect and admiration they continued to feel for their loved one. Some participants highlighted the character and uniqueness of their loved one, including personality traits or meaningful memories. Some viewed their loved one's decision to pursue MAiD as "courageous." Another participant described her disappointment in her loved one's decisions and character, feeling it demonstrated a lack of faith. The degree of respect and admiration felt by participants for

their loved one contributed to their experience of MAiD both in their ability to support decisions related to MAiD and in their ensuing grief. Knowing that other people had respect and admiration for one's loved one also seemed to impact how family members experienced the time leading up to and after their loved one's death. When family members felt regard and admiration for their loved one and felt that their connection to their loved one was close, they tended to describe the loved one's decision to receive MAiD more positively.

The following I-poem describes Deborah's respect and appreciation for her husband. Her admiration for her husband was a dominant voice throughout her entire story.

Admiration

I called him "a quiet certitude"
I mean that's what I miss about his being dead is that –well, I guess I don't miss about his being dead;
I guess I miss it about him being alive—is that he was just that constant, that constant presence that you could just turn to and rely on.
I referred to him in my presentation as "the shepherd of the family"
I learned so much from him
I just . . . the time we had together was just second-to-none.
I guess it was—'97; yeah, it was 20 years that we had together
I mean we were both pretty old by that time
I mean we just had a great time together; it was just lovely. It was so much fun;
I would not have traded it for anything.
I know a lot of different people; and nobody is like him.
I'm so happy that I knew him
I'm so happy that we had those 20 years because I mean I never would have known what I missed, but it was just . . . it just showed me a side of life I would never have seen without him.
I loved him most.
I am just every day grateful that I knew him for over 20 years
I just always felt secure with him
I've still got him here.

In addition to having her own sense of admiration for her husband, Deborah also felt that others respected and admired her husband. She explained:

> you know, [he was] just a neat guy; he was in the background working away, and people would come to him, and they just knew that he would remember what they had said – he was a good listener – and he would usually ask questions about what they were doing. People really loved him.

Deborah's regard for her husband, and the knowledge of other people's respect of him, contributed to her sense of peace with his decision to receive MAiD. She trusted his character, his decision-making, and the strength of their relationship.

The sense of connection or togetherness uniting family members with their loved one varied among participants. Some participants felt that decisions around end-of-life brought them closer to their loved one, while others felt a disconnection from their loved one as MAiD got closer. For example, Tabitha recalled feeling her husband began to disconnect from her and from the world around him after he made the decision to receive MAiD. Megan described how she felt she needed to help her father realize the memories he was leaving her mother with, and she begged him to consider the fact that their life would go on after his was over. She described her relationship with her father as "unhealthy" and recognized that this fact impacted her and her families' experience before, during, and after her father died.

In contrast to this, Landon and his wife shared a close connection. He described how this closeness impacted his experience of loss saying, "It was the most gut-wrenching moment of my life, actually. Here I am . . . I'm losing my best friend, my partner; we did everything together; we were inseparable . . . We were very, very close. And that's what probably hurts the most." The following I-poem demonstrates Landon's continued bond with his wife, through memory.

Memory

I have a very good memory
I was sad for a long time
I would go to bed at night and I would just look at my wife sleeping in bed, right, so soundly, but so weak and so helpless
I would just bring up things we did in the past
I'd go, "Remember when we did this; remember when we did that"
I knew she was going to pass
I got more and more emotional
I would just think, right, "Oh, my God, I'm with her for 39 years," and, say, "she's not going to be with me anymore. She's not going to be with me forever
I think that hit . . . especially the night before
I think of when she got in the bed, and [him] and I, you know, are on either side of each other, it was . . . oh . . .
I'm just getting good bumps, you know, now thinking about it, right.
I can replay . . . that day is so vivid.
I can replay it over and over and over again
I know she'll never come back
I also know . . . I don't want to be selfish about it
I also wouldn't want her around like this. It would be any good, right, and it actually would be downright cruel and torture, right.
I'm losing my best friend
I was very, very emotional
I just couldn't stop crying
I just really couldn't stop crying
I knew that I had to let her go
I'm always going to remember
I'm going to call it "3/11"
I know people have 9/11, right . . . I know people talk about 9/11 with the towers
I call mine "3/11"
I can still . . .
I know how longs she's been gone; she's been gone, like, six months and two weeks, roughly
I count it
I don't know if it's healthy to do that
I say to my wife . . . you know, I look at her picture . . . I go, "It's not a good day today."
I say that every Sunday
I can remember everything about that day, actually.
I think I've been very thorough
I remember
I can remember everything
I've got a very good memory; sometimes, I've got too good of a memory
I can remember things about this . . . and sometimes, I would rather forget
I guess I can't forget
I guess that's my . . .

I guess that's the burden I have to carry

The regard felt toward one's loved one, the perceived respect and admiration of others for one's loved one, and the sense of connection felt between participants and their loved one impacted both how family members view their loved one's decision to receive MAiD and how they experienced the loss itself.

Shared decision-making. Another factor influencing family members' experience of MAiD was their degree of involvement in decision-making. For some participants, the decision to receive MAiD was made independently by the loved one, and the family member took on roles of observer and supporter. For others, the decision was clearly a joint task. Some participants described feeling that they and their loved one were "on the same page," but ultimately the decision landed on the loved one receiving MAiD. Some participants described coming on-side of the decision over time, and others explained that they wanted what their loved one wanted right from the beginning. It is worth noting that although some participants described being fully supportive of their loved one's decision and effectively "giving one's blessing" to proceed with MAiD, their support did not necessarily reflect their own self. In other words, loved ones could be very involved in the processes surrounding decision-making, without necessarily feeling that their own values or beliefs were integrated into the decision that was made.

Deborah believed strongly that MAiD should be centred on honouring the individual's choice. She described feeling that it was her responsibility to discuss the decision with her husband, but ultimately support whatever her husband decided. She explained that bringing in family members values or beliefs could would "just add complexity." She said,

> it's the person's life, and that's what the whole argument's about, isn't it? "Do we have control over our lives? So this is your life . . ." this is *his* life, in fact, and he wanted it to be this way. So whether I wanted him to do that or not, is really not the issue for the medical people; that's an issue for him and me when we talk between us. But once the decision's made, I think it should be him. The family caregiver really shouldn't have a say in it.

Deborah and her husband were on the same page when it came to his decision to receive MAiD. In listening for the "we" voice throughout her narrative, the decision-making process was a shared negotiation. The following excerpt from an I-poem highlights the shared negotiation that Deborah and her husband navigated over time.

A Shared Negotiation

I remember him saying—like, we both had said, "We just don't want that to be the case. We want someone to be able to, like, end it for us or for us to end it when we can't live the life we want to live.
I mean he was breathing
I mean he had long stopped playing golf.
I thought, "You have never seen a loved one living like you know he does not want to live, and who had chosen to do this.
I guess that's sort of the part of me that got involved in it.
I thought, "This is going to happen on his terms. He's going to decide when he dies"
"I'm not going to be ready for it."
"I have to be there and just see it"
I wasn't sure I could do it because it's . . .
I don't know . . .
He kept saying he wasn't afraid to die, but he said, "I don't really . . . I don't want . . . "
He said, "I'm not afraid to die, I just don't want to leave you."
I said to him, too, "I didn't want him to leave me,"
I knew he had to
I knew there was no choice
I went to [the doctor's] office on the way out of the hospital that night
I said, "Can you clarify? What do you mean by, "a couple of . . . [years]?
I kept thinking, "If I could just get him to the cottage, he'd be better"
I guess that night,
I mean I was devastated because [he] didn't know this
I did not want to tell him what the doctor had said in the second conversation
I thought, "There's no way I'm telling him, anyways. If he thinks 2 years, that's great"
I mean I could see the diminishing health.
I said to me friend, "If I can just get him to the cottage, I know he'll be better.
I mean it's false hope in retrospect, but at the time, it's not false.
I knew that he wasn't going to live very long
I knew that that was going to be his choice

I mean he was just very sick then
I just can't understand how [he even signed the document] because he had absolutely no strength
I had to put the pen in his hand
I know he thought this, too—we thought he was just getting older.
I said, "Oh, what . . . come on, don't be so silly. Of course you'll be here"
I mean he couldn't do anything.
I mean, in retrospect now, I know everything was just shutting down; nothing was working
I mean I was incredulous
I thought, "This is cruel and unusual punishment. There's no way this man is going to be able to live for two years. I don't know care what you do to him"
I can't remember exactly what he did then
I think he did go for one chemo treatment
I mean I thought he was going to die. It was so bad.
I had to phone and say, you know, "We're just not going through with it because . . . this is going to kill him, like, faster and he doesn't need that"
I think he had put the process in place by then through the [organization] nurse.
We didn't know the rules
I was right there with him because we were kind of going through each question, making sure that we were all on the same page about it
I had my hand on his chest the whole time that they gave that injection
I was just sort of sitting . . .
I was, like, sort of, you know, nose-to-nose with him,
I had my hand on his chest
I could feel his breathing
I could feel it. And then it stopped
I knew that he was dead

As her husband's health declined, Deborah gradually came to terms with the reality of her husband's health. Though they each had to accept the fact he was dying in their own way and time, they were eventually able to get on the same page regarding his decision for MAiD.

David described the process he and his wife, and their family, went through in making decisions about MAiD. Similar to Deborah, David felt involved in the process. He also felt that ultimately MAiD would be his wife's decision. He explained how the entire family "knew it was her call; it was for her to decide when she had to have that

service. And she lasted nine months." As in Deborah's case, for David and his wife, the decision-making surrounding MAiD was a process that evolved over time, both for them as a couple and for their family. David summarized:

> For us it was sort of a process . . . We had talked about it – not a lot – but it was a part of our life. And making the decision was just making the decision that we knew she had to make and I had to support . . . it just flowed along like that. We were very accepting of death as a part of life and we talked about it. And [my wife] was very, very much at peace with herself, and she was very satisfied with her life . . . And we just accepted it that way. So it wasn't any event; it was a sort of a process, I don't know how to explain it.

For both David and Deborah, regard for their spouse and a felt close connection with their loved one are evidenced in how they involve themselves in their loved one's decision to receive MAiD.

To summarize the countersubject running through the fugue, the relationship to one's loved one throughout the entire process leading up to, during, and after their loved one's death was significant to how family members described their experience of MAiD. This countersubject acknowledges the "we" voice heard throughout participants' narratives. It also considers how family members' experience of MAiD are impacted by participants' regard for and connection with their loved one, which, in turn, shape family members' involvement in shared decision-making related to MAiD. The subject, relationship to self, and the countersubject, relationship to loved one, move together throughout the fugue, providing listeners with an appreciation for the complex factors influencing the unique experiences described by participants. The subject and countersubject described above can be heard throughout the four voices of the fugue that follow. By incorporating the individual voices listed in Table 2, four augmented voices have been identified and brought together to provide a richer sense of the broader ways in

which participants' relationship to themselves and their relationship to their loved one impacts their own experience of MAiD. With an introduction to the subject and countersubject, listeners will be able to identify these melodic motifs as they move through the following voices.

Voices of the Fugue

Reflections on how family members viewed themselves—their unique personhood—as being welcomed or not welcomed into all that encompassed their loved one's experience of MAiD, as well as reflections on how the relationships between family members and their loved ones informed the experience of participants, will be examined further through the four voices of: (a) witnessing, (b) caregiving, (c) honouring choice and supporting dignity, and (d) surrendering and letting go. In a fugue, each voice has a distinct range, that at times overlaps with neighbouring voices. Both the subject and the countersubject can be heard moving through the voices, and it is this contrapuntal movement that creates dissonance, harmony, complexity, intensity, and even beauty. Emphasis is not placed on separating the voices, subject, and countersubject in a fugue, but rather on listening for what happens when all distinct parts are carefully woven together. While these voices are in many ways similar to what one might hear in accounts from family members whose loved one has had a non-MAiD death, the unique ways in which MAiD influences these voices will be highlighted throughout.

Voice 1: Witnessing. Several participants spoke about their felt sense of helplessness in watching their loved one's health deteriorate. As described earlier, the degree of suffering family members bore witness to was enough in some cases to actually change their perspective toward MAiD. The suffering participants observed in their loved

one was described as physiological, emotional, and physical. Several participants specifically mentioned the terror their loved one experienced in the face of potential, or in some cases, certain cognitive decline. Across the data, there was an acknowledgment by family members that MAiD offered a way out of profound suffering and that without MAiD their loved one would face a threat to their quality of life. This appreciation for the degree of suffering facing their loved one impacted how family members chose to support their loved one in their decision to receive MAiD. Participants described feeling that if they did not support their loved one's choice to end their suffering, they would be inadvertently accepting their loved one's certain fate of ongoing, irremediable suffering. Family members could not ignore the suffering that they saw, nor could they ask their loved one to continue to suffer for the sake of the family member. Confronted with such suffering, some family members felt they had to release their loved one, intentionally deciding, at least at a cognitive level, to want what their loved one wanted, pushing aside doubts or feelings. The impact of bearing witness to suffering on the experience of family members is illustrated in narratives from Landon, Jeoffrey, and Tabitha.

Witnessing his wife's suffering left Landon feeling helpless, as captured in his I-poem:

Helpless

I took her to the hospital
I felt so bad for her
I was helpless to do anything
I just saw . . . you know
I was absolutely helpless
But I supported her in everything that she did
I would actually sit with her and do them (pursed lip breathing exercises)
I'm not saying it improved a lot, but it gave her a bit more quality
I just noticed, any little thing . . . became harder.
I felt very helpless
I couldn't do a thing except give her, you know, except give her my love and moral

support
I was like the caregiver, year. Yeah, I was actually the caregiver

Landon could not do anything to fix his wife's suffering and that left him feeling that his only option was to support her in her decision for MAiD. He recalled watching her lose more and more independence:

> I would go to bed at night and I would just look at my wife sleeping in bed, so soundly, but so weak and so helpless; at the end she was as helpless as a newborn, really. She just couldn't do anything anymore; she couldn't do any work in the house; she would make me a meal, but it would take everything out of her. She used to pride herself on cleaning up in the kitchen after the meal, leaving the kitchen spotless. But I would say that, about the last month of her life, she couldn't do that. And she also said, the day before she passed, she said, "Landon, I'm so sorry that I ruined your life." . . . And that's just like . . . oh, boy, oh, boy, did that get me.

Bearing witness to his wife's suffering overwhelmed Landon. He remembered when the doctor asked him how he felt about MAiD:

> I was all for it, because, you know, I just couldn't stand to see her suffer. It was like somebody was suffering, suffering terrible. And there was no quality of life for her; so, you know, I just had to let her go.

Landon described this impossible predicament he found himself in: his wife was facing immense suffering, and he was unable to stop it. Yet, his heart broke at the thought of losing his closest friend. He reflected on his painful memory:

> you know, it was each day before, each successive day that, you know, I knew she was going to pass, I got more and more emotional. Like, I would just think, "Oh, my God, I'm with her for 39 years," and, say, "she's not going to be with me anymore. She's not going to be with me forever." And, you know, that really hit, right, especially the night before. Because she said the day before that she was really scared. She goes, "Landon, I'm scared to die. I'm scared. I'm really scared."

Seeing his wife's suffering was enough to change Landon's perspective on MAiD. The following I-poem shows this transition.

Beliefs and support
I know, many years ago—many, many years ago—I would have never supported those thoughts [about MAiD]
I had a complete reversal of thought
I fully support her wishes
I was fully supportive, actually
I was, "If there's anything I can do to help, just please let me know"
I loved her with all my heart
I couldn't stand her being like this
I actually had to let her go
I had to become unselfish
I just had to let her go
I still think it's like uncharted waters, right?
I know there's medical stuff involved with MAiD, right? But you have to put a human aspect into it
I think you have to be understanding of what the patient wants
I know there's probably a lot of family squabbles
I don't think there should be anything that should hold them back, especially if they are of sound mind
I don't think there's anything in this world that should stop them
I actually don't see any fault in the process
I'm happy it was thorough
I actually think it should be thorough
I think that it's hard
I do like that it's thorough
I think it has to be thorough to prevent any sort of lawsuits

Tabitha also bore witness to incredible suffering. She explained how hard it was to see her husband's health deteriorate. She recalled one of their final conversations:

> So he did say to me, "You know, I won't get to meet [the baby], but I will one day meet him in a different sense. But," he said, "I've experienced grandparenthood, and my life feels like its complete now. I've done everything; there's nothing else I want to do; I don't feel like I'm missing out. I just . . . I'm tired. It's time for me to go." So I could see that. I wanted what [he] wanted. And it was very difficult to see your loved one, you know, physically and mentally, emotionally, just a shell, so . . . .

The decline in physical health as well as the change in perspective of her husband was difficult for Tabitha to observe.

Both of these participants show how witnessing the suffering of their loved one

impacted how they reacted to their love one's decision to receive MAiD. In different cases, the suffering challenged how participants supported their love one's decision and even resulted in a shift in beliefs and values related to MAiD. In many cases the suffering witnessed by family members grew their support for their loved ones' decision for MAiD. This influenced their own actions and choices in the time leading up to and during MAiD, and this is reflected in how they tell of their loved one's death after their loss.

Voice 2: Caregiving. Witnessing such suffering, and feeling helpless in the face of it, participants spoke much about their experience of caregiving for their loved one. Many participants identified as the primary caregiver, or caretaker, for their loved one and note that it was not until their loved one was deemed "palliative" that they received any formal caregiving support. Caregiving roles included providing physical and emotional support to the loved one, attempting to mitigate pain, confusion, and further grief for other family members, and serving as advocate for their loved one who chose MAiD. Participants described how, in many ways, caregiving became a way to counteract the helplessness they felt, as it made them feel closer to the loved one they were preparing to say goodbye to. Several participants expressed some reluctance in handing over care to others, as this had been their way of connecting with their loved one, protecting them, or even maintaining some sense of control. Along with providing care for others, participants also described a range of experiences in receiving caregiving efforts from others. Though relationships with others will be explored in the episode section of the fugue, it is worth noting here that these external forms of support for the participant did impact how the family member provided cared for their loved one, ultimately impacting the family members' experience of MAiD. Through all of this, the

question arises of whether the burden of caregiving felt by loved ones contributed to one's decision to receive MAiD. While family members often became caregivers to their loved one at the end-of-life, participants did describe their experience of caregiving in light of MAiD, noting additional unique complexities that were felt in an already taxing, though in many ways meaningful, role.

Family members were tasked with various responsibilities as caregivers. Landon described the weight he felt when his wife made it clear that she expected him to ensure she died in a "dignified way." He explained, "she wanted to go in a dignified way, whether it was to fly over to Switzerland or one of those places in the Eurozone where it's legal, or to fly somewhere. She wanted me just to make sure." His caregiving included advocacy.

For Jeoffrey, his caregiving role grew over time. He recalled:

> [My wife] was a clean freak, and we used to share the housework; we never had kids so we always shared everything. But, even without asking, I just slowly had to take it over. I noticed that she wasn't doing it, so I just did it. So you just end up doing more and more and more . . . And then it just basically became 24/7 for me . . . that's when it started to run me into the ground.

Reaching his limit, his wife and him finally decided that it was time for her to move to hospice.

Also identifying as his wife's primary caregiver, David shared the relief that came with his wife's decision to receive palliative care. He explained:

> We got into the hospital, and we got two young doctors, and they said, " . . . there are four options. You can keep going to doctors' offices like you are, and that's obviously not working. You can come in the Comfort Care in the hospital here." – we'd never heard of Comfort Care – "You could have Palliative Care, possibly, depending on how things work out. And then, the option is medically-assisted dying." And we were so relieved to talk about . . . they said to us, "You're in the process of dying," and we were so happy to be able to talk about it. Because [my wife] and I had known that and had spoken of it for about six months, and we

> couldn't understand why doctors weren't telling us that. So, finally, we were in the right situation. And she was in the hospital for three weeks, and then she came home in Palliative Care. In Palliative Care, I had complete help, you know. But, up until then, I was carrying it myself; that was about two or three years . . . It's very difficult coming out of that situation.

Palliative care for his wife meant that David and his wife could acknowledge the reality of their situation, understand the illness trajectory, and get much needed support. This support allowed his wife to continue living nine months after receiving approval for MAiD.

Tabitha remembered feeling exhausted after years of caring for her husband. The following I-poem expresses her exhaustion and her frustration with the lack of respite services made available to them.

Exhausted

I think, at the end of the day, it was the depression that got him
I quit work to take care of him, to stay home full-time and be with him
Like I said, there was two monster living in our house with [him]—the depression and the cancer
I got burnt-out
I think he was—yeah, it was June—he was in Hospice for three weeks for a respite
I needed that break
I went online, back in December
I said, "You know [husband], I'm not suggesting this.
I'm just giving you some options, now that it is legal"
I guess he thought about
I guess he was doing a lot of online research on his own
I'll never forget the day
I guess he just needed . . . that final tipping
I'd already told him, "I stand by you and, whatever decision you make, I respect and honour"
I sensed a . . . I could feel [him] starting . . .
I could . . .
I sensed it; yeah,
I knew that something was happening
I have a girlfriend who lost a husband to colon cancer that had moved to his brain. And she described to me how he became not the fellow she married and just became very disjointed and disconnected
I thought, "Oh, my God, it's gone to his brain, because that's what's happening"
I'm absolutely exhausted again

I got his sons and their wives to look after [him] for the two nights I had gone away
I had people during the day looking after him as well
I phoned him from [place] and said, "How did your appointment go? Did you get your meds changed?"
I knew right then and there . . .
I don't know how else to describe it—it's like this big, huge snowball coming down the hill. And you know it's going to hit you, but you just don't know when.
I just kind of put it out there
"I can't fight this"
"I have to allow and just honour and just do the best I can"
I was struggling
I have to say, "Shame on [city] on so many levels
I'm not very impressed with the dying process in [city]
I'm not talking about the staff
I'm talking about . . . the Hospice, they only take people in the last three months of their life; they don't do respite
I truly believe that's terrible

The interrelatedness of exhaustion with the lack of support described by Tabitha in this I-poem demonstrates how MAiD could be viewed or experienced as offering relief to one who has been providing such intense care to their loved one. Though she was quick to clarify that she was not "suggesting this," she did not hide her support for MAiD and her frustration with a lack of respite services. As seen here, the inevitability of death, the increased care demands, and the lack of support for caregivers contributed to Tabitha's experience of MAiD.

Megan described the caretaking role that she maintained throughout the entire experience surrounding her father's death, extending through to the funeral. She emphatically stated, "No, no, it [death day] was very much not about me. I was just caretaking other people that day, for sure." When asked if she felt like she said goodbye she said:

> I don't think I really said goodbye to Dad. I was mostly just managing the rest of the family. To give you a picture, Dad had a funeral. On the day before, they had a "viewing" of his body, the casket and the church. In the picture of the people

> following the casket out of the church, I'm not in the picture because I'm taking the picture. Because one of the funeral organizers said, "Oh, here's the camera. Your Mom wanted pictures." I was like, "Okay, my Mom wants pictures," so I was taking pictures. And then, afterwards, I was like, "I shouldn't have been doing that. I should have been behind the casket, you know, walking with everybody." Everybody else was doing their "Goodbye, Dad" stuff, but I was managing things in the background.

In this case, caretaking other family members meant that Megan did not feel she could take up space for herself, or tend to her own needs, even on the day of her father's funeral.

Participants described the weight that their role as caregivers for their loved one, and in many cases other family members, added to their already difficult experience of loss. While acknowledging their exhaustion, some family members emphasized their desire to be the one to provide care for their loved one. Others seemed to suggest that caregiving, especially providing for physical needs, added to their already heavy burden of preparing for their loved one's death. A family member's felt sense of ability or capacity to provide adequate care for their loved one(s) impacted their sense of satisfaction in their involvement with their loved one's death. It also seems possible, as reflected in these accounts, that without satisfactory supports in place for both the individuals experiencing such suffering at the end-of-life and for their family members, family members and individuals experiencing suffering became more open to MAiD as an option.

Voice 3: Honouring choice and supporting dignity. For many participants, their approach to MAiD and their experience with MAiD was driven by their desire to honour their loved one's decision. In the face of much suffering—whether actual or predicted—and as an extension of their role as caregiver, family members sought to honour the

autonomy and choice of their loved one. Some family members spoke of how their decision to support their loved one was their way of accepting, and not ignoring, the reality of approaching death. MAiD provided family members and their loved ones with a sense of control in a context of illness that leaves little room for agency. Some opportunities made possible with MAiD included opportunity to make final arrangements, to say goodbye, and to have one's loved one cognizant for their final moments. All of these factors contributed to family members feeling their loved one had died with dignity. Many described their fear that without MAiD, their loved one might die without such dignity. Several participants shared the sense of peace they still experienced knowing that their loved one made their decision for MAiD with certainty. Even in the midst of doubt, family members rested in the fact that they honoured and supported this final choice of their loved one.

Being able to honour a loved one's autonomy and choice offered agency to family members who felt helpless to "fix" the pain they observed in their loved one. Jeoffrey explained how this newfound sense of control impacted his wife and his own experience:

> One of the things that one of the Palliative doctors told us when we were first talking about this, [was that], "Some people," – and this is all personal preference – "but some people, it's like you take control of your life back." So, instead of cancer beating you up, and beating you, and beating you, and beating you, you now take control of your life. And you basically say, "F--- you, cancer. I'm in charge now." And that was the most amazing thing because [my wife] was on about eight shots of morphine a day as well as a 50 mg Fentanyl patch. And it dropped to four or less [once the decision was made].

Jeoffrey experienced relief when he saw how his wife's decision to move forward with MAiD resulted in decreased physical suffering, as evidenced by fewer required medications. Supporting her decision therefore became a way he could help to reduce her pain.

Along with offering a sense of control and agency in the face of illness, MAiD also provided family members with a means to accept the reality of approaching death. For David and his wife, MAiD allowed them to surrender control and to open themselves to the reality of dying. David explained the more passive approach that he and his wife took:

> We were very, very fortunate. You know, [my wife] and I used to say that we believed that our life was a series of what we called 'synchronicities', where the right things happen at the right time, and things were just meant to be. And we really felt that the pieces fell in place for us at the right time; we got to see the right people, and, you know, got the right services and so on. So we . . . it [MAiD and the process of dying] happened very well for us.

Their more passive acceptance of the reality of their situation did not mean that David and his wife did not proceed with careful and intentional planning. David recalled the thoughtful planning his wife put into her final moments:

> And [she] got a new dress for the occasion; she had one of her friends go out and bring in some selection, and she had selected a red top and black slacks and red earrings to match. And she sat in her favorite chair in the living room, and she spoke to everybody. She called each one forward and spoke to them for about three or four minutes about their memories, and thanked them. She spoke to all of us; and then, our granddaughter sang [my wife's] favourite song, "Smile" . . . During that time, I was sitting with her – beside [her] – and holding one hand, and the boys were sitting on the other side holding her other hand . . . and then, she spoke to everybody. And that's when she and I had a chance to say our last words. And she'd talked to the boys, of course, before me, and then, me; and then, she said to the doctor who was behind the chair, sort of out of the way. And then, she just said to the doctor, "It's time." So everything was done beautifully.

David described the planned event as filled with love. He explained that by having their closest friends and family present, he did not have to tell everybody that she had died, easing his burden of loss. David's description illustrates how MAiD offered an explicit timeline to prepare and personalize MAiD arrangements and funeral arrangements. This

timeline, and the certainty of the timeline's ending, created opportunities for finding closure and saying goodbye.

Ending on "good terms" and saying goodbye were ways family members could honour their loved one and their relationship with them. As someone who tried to make the best of any situation, Jeoffrey echoed David, describing the benefits he sees with MAiD:

> Now you know; the date is set. So now, as your friends come to visit you, you have your final conversations . . . You know, " . . . I've known you for so many years; you've been such a wonderful person; you've been an inspiration to me; you'll be missed," blah, blah, blah. "I'm happy for you because I don't want to see you suffer anymore. It's breaking my heart to see you suffer." So everybody gets to say their goodbyes.

Speaking lightheartedly, Jeoffrey pointed to the way final goodbyes offered by MAiD provide a unique opportunity for family members to verbally affirm their loved one and to express their love for them.

For Sandra, MAiD provided opportunity to create a supportive environment for the anticipated grief that would come with her husband's death. Knowing their final days were limited, her and her husband enjoyed the "best five days that we had had for years." In this way, MAiD provided a way for them to honour each other and their relationship. She shared how MAiD allowed them to live in the moment:

> My two sons both live locally, and [my husband] was very concerned about me, and he wanted me to share with them so that they would be available for me on the afternoon that his death was to take place. So I did that just . . . three days before the date, I told them [about the decision for MAiD], and asked them if they could come to the nursing home. And, after that, he really didn't talk a lot about his death; he was just so contented. We had the best five days that we had had for years. We just talked about our kids and our grandkids and our travels and all about the past – not the present and not the future. I say "talk" – he slept a lot because he was really very weak – and a lot of the conversations were one-sided, but he was participating, and he was very content.

By knowing the date and time, Sandra and her husband could intentionally create meaningful memories of their last days together.

Along with these practical opportunities provided by MAiD, some family members felt that the degree of certainty that their loved one demonstrated in their decision for MAiD offered and continues to offer a sense of peace. Though Tabitha admitted that she experienced doubts at times and found herself second-guessing, she rested in the calmness and certainty displayed by her husband until the very end. The certainty he maintained until his final moments and his involvement in all aspects of his death made their final moments together very meaningful. She explained:

> he had a very great sense of humour; and [the doctor] and her nurse were in the next room mixing up the cocktail, and it was about five minutes before the time. And he said, "Let's get this show on the road." Like, he could not wait; he was not nervous or anything; he was . . . ready. He laid down on the bed, and he goes, "Where's my wife?" He holds his arm up like this, and I laid right down in beside him . . . My head was on his shoulder and my hand was on his heart. And the boys each held his hands, and then the girls held the boys; and then my sister, and his sister, they were just holding his legs. And then my sister had a beautiful . . . just something she wrote, with soft music in the background. And she just read what she'd written, and it was beautiful . . . And he knew what she was saying, because we read it to him before he passed . . . So he had a hand in all of it. He chose the music that played while he was passing . . . . We had flowers in the room, and we had a prayer flag on the blind . . . And, yeah, so it was beautiful; it really was. And it wasn't . . . I'm going to say four minutes; I don't think it was any longer than that . . . . And he almost had a smile on his face . . . . Yeah . . . . So that part was good.

In the midst of uncertainty and profound loss, Tabitha was still able to look back with positivity toward the event itself, knowing with certainty that this was what her husband wanted.

To summarize the voice of honouring choice and supporting dignity, family members described how MAiD offered unique opportunities to honour their loved one, and their relationship, and also to receive love from their loved one. Participants

explained how honouring the autonomy and dignity of their loved one by supporting their decision to receive MAiD offered a sense of control, agency, and peace in a time of uncertainty and loss of control. Many participants remained grateful for the opportunities MAiD provided to create meaningful memories with their loved one and to say goodbye. Having experienced such loss, many family members found peace in the knowledge that they honoured their loved one and their relationship with their loved one by supporting their decision to receive MAiD.

Voice 4: Surrendering and letting go. While the honouring choice and supporting dignity voice elucidates how MAiD offers opportunities, such as providing a sense of control during a time when family members and their loved ones may experience a loss of control, a fourth voice, surrendering and letting go, illuminates how MAiD also adds challenges to an already difficult time of loss. While acknowledging the unique opportunities presented with MAiD, participants also spoke of the ways their loved one's death required a form of surrender. Many participants spoke of losing or giving up control—noting that at times this was voluntary, and other times it was forced. Family members spoke of the finality of MAiD and of the intensified emotional, relational, and physical experiences that they felt as a result of their loved one's impending death. Some described feeling a sense of urgency or increased pressure during their final days with their loved one. Participants also described surrendering their own certainty, which resulted in some fearing they missed something important or perhaps did not say a proper "goodbye." Others carried additional anxiety because of the added obligation they felt to help "prove" their loved one's eligibility for MAiD.

Jeoffrey described the loss of control he experienced as he observed his wife's physical decline and as she needed help with her care. He explained how he felt the day his wife pulled out the forms for hospice:

> On one hand, [I felt] relieved, because I knew I was at the max that I could do, not just physically or emotionally, logistically, too; you know, the whole shower-upstairs thing, sleeping in a recliner. You know, get her into bed with a walk-in shower; you know, there is some benefits to [hospice], and the 24-hour care. And I've always been aware of, "You can overdo it," and, "If I don't take care of myself, I'm no good to her." . . . Then, there's that bit of shock of . . . because you go over there, and now, I'm hands-off, right. You know, "Here's the med chart. Okay, Jeoffrey, you're done, you're done," you know. So then . . . you just have moments of, "At least, I always knew I was in control of the situation."

Unable to stop his wife's approaching death, Jeoffrey strongly advocated for the control that MAiD offers. Yet, he also navigated the tension felt in accepting the control that MAiD offered and giving up the control that MAiD required.

The following I-poem demonstrates this felt tension of trying to stay in control, while simultaneously letting go.

Final Days

I don't want to pack up her room before that in front of her
I want to be fair to you and fair to the next person that wants this room
I said, "How about this? I can guarantee you I will be here by 10:00am tomorrow morning. I'll have that room clean by 10:30"
I mean I've been through my sister's death, my Mom's death, my Dad's death, [her] Mom . . .
I didn't really need his help [speaking of his friend who offered to help]
I mean it was just some knickknacks, and a couple bagsful of clothes, right
I didn't have to do it alone.
I came home about 2:00 [after packing her room]
I showered
I changed
I ended up just wearing dress pants and collared shifts, right—semi-casual, semi-cleaned up.
I go back over there
I never, ever told anybody, but I just didn't know how that was going to unfold
I accept what life gives us
I told you that we actually went for dinner first, right
I didn't think I would be able to eat

I couldn't figure out . . .
I didn't have a drink
I probably ate three bites . . .
I said, "Unfortunately, [wife's name], I said, like, "we'll leave here at 6:50, but she said, 'Do not come before 7:00"
I must have been home when the conversation came about
I was quite taken aback, the last thing I would have wanted to do
I don't know
I was losing my shit
I was just . . . and the front of my shirt was just soaked.
I completely lost it
I had to get [the wheelchair] back to the Red Cross
"I'm taking her up; I'm not bringing her back"
I'd certainly rather have that personal emotion than, a week later, [her] falling in the hospice . . .
I'm not saying that was a bad experience; it just was . . . that as the true, in-you-face reality of the situation
I think she had removed herself
I don't remember too clearly
I said to her, I said, "This wasn't the fucking plan"
I mean we met late in life
I'm saying to her, "So I don't want to lose you, but I don't want you to suffer anymore"
I think she said to me, "Well," you know, "Only you know how much I've suffered, Jeoffrey, only you know"
I'm sitting on a low stool right beside her
I'm holding her hand
I let [her] hand go because she was hugging everybody right
I felt the last heartbeat
I probably stood there for . . . sat there for like, a minute
I was tearing
I wasn't crying
I wasn't' blubbering
I just . . . crying, trying to be peaceful
I just stood up
I just kissed her on the forehead, and told her I loved her
I walked out of there

In this I-poem, we see Jeoffrey managing both the practical aspects of preparing for his wife's death, including packing up her belongings and returning her wheelchair, as well as the realization of the finality of this event. His emotions hit him hardest when he realized this was the end.

For many of the participants, this finality of MAiD added a unique challenge. Landon explained, "the hardest part about MAID is, there is finality; it's the end of a process, right." As mentioned earlier, Deborah also felt a weight because of her sense of finality, noting that with MAiD, "there is no turning back." Family members recognized that the nature of MAiD promises a certainty around the time of death, as well as an inevitability of death, once medications are administered. For some, having a planned timeline for MAiD added a sense of urgency and pressure. For example, as shown in the I-poem "Exhausted," knowing the time of her husband's death left Tabitha, paradoxically, feeling a loss of control. For those with unresolved familial conflict, this expedited timeline added pressure to an already tense context. In the midst of conflicted relationships, the timeline, or countdown, of Megan's impending father's death added additional pressure to her family. She explained, "Mom and I often talked about it since then, like, 'What would be worse? Dad getting hit by a bus or all this careful planning to *the* date and *the* time. You know it's going to happen.' It's just like, you know, psychologically torturing." Megan acknowledged that, in theory, MAiD could have provided opportunity for conflict resolution and saying goodbye. She noted that for her family, however, it simply made the experience surrounding her father's death even more difficult, adding that she herself was still saying goodbye. She explained that MAiD did not offer the closure that it could have, "if we'd been a different family, and my Dad had not had the problems he had." Her grief had been further complicated as a result of her experience with MAiD.

Deborah also described feeling uncertain about how she said, or did not say goodbye, in the lead-up to MAiD. This uncertainty around her and her husband's

goodbye "plagued" her. Although some family members reflected on how they said goodbye, the weight of this question for Deborah was significant in her experience of MAiD.

Did we say goodbye?

I think, "Did I say goodbye enough or with the right intention?
Because we didn't really ever say goodbye
I don't know whether we just couldn't face it . . . or we thought it was so obvious we didn't need to say it?
I don't really know where our heads were at, but we didn't actually say goodbye
I mean I said to him many times like, "There's no way I'll ever marry again if you're evening thinking this after you die"
I still believe that
I just don't believe . . . although I know I would never marry again
I mean it's a hard act to follow
I never said goodbye to him
I never said . . . yeah
I just never said goodbye
I would take the paper in and I'd say, "Do you want to hear what's happening in the news today?"
I would tell him what was going on in the world, you know, and we just kind of carried on.
I mean I said goodbye to him certainly after he died, but he didn't hear it
I mean, when he said he didn't want to leave me, that was . . .
I guess that was kind of his goodbye, but that was a few days before he actually did die
I guess we were a little unconventional
I don't know what other people do when the person is dying
I don't know how you would orchestrate that, but we didn't do it anyways
I guess it was [really beautiful]
I would sit by his bed and read the paper and tend to him and give him something to eat or drink or whatever he was . . .
I was certainly there tending all of those things
But, I don't know, it was one of those things that you don't really plan, but it falls into place, and that's just how it fell into place.
I don't know, "goodbye" sounds sort of like a living thing to do.
I don't know why we didn't say goodbye, but we never did
I don't know, like, it just seemed to be natural; like, it just seemed to be the way that things should be
He knew I was doing what he wanted
I think he found some comfort in that
I hope he did

In this case, even though MAiD allowed for the opportunity for her husband and her to intentionally plan his final days and their final conversations, Deborah still questioned whether she ever really said good-bye.

Other ways that family members surrendered their feelings of uncertainty toward MAiD are seen in how they navigated the screening processes required for their loved ones to be deemed eligible for MAiD. While some described the screening process as onerous, others emphasized how the thoroughness of the procedures leading up to MAiD actually helped them trust their loved one's decision. They credited this to hearing their loved one repeatedly explain just how sure they were that this was what they wanted. Participants described how their own uncertainty, before, during, and after MAiD, was softened by the certainty they witnessed their loved one express to the assessors. By supporting their loved one in the application process, however, family members felt they had to give up or at least minimize their own uncertainty. Landon described his uncertainty in his role as husband in the processes and procedures leading up to his wife's death in the following I-poem. For Landon, the thoroughness of the screening process gave him confidence when he himself was experiencing the opposite.

Uncertainty

I think last February, if I'm not mistaken
I don't know, I guess you can call it a first screening of about 20 minutes
I was involved in the screening process a bit
I was all for it
I just couldn't stand to see her suffer
I just had to let her go
I guess that it's, end of story
I think he had to
I think he was also seeing if [she] was of sound mind, right
I thought a very meaningful process was how it was explained by the doctor
I actually didn't have a big say

I was just giving my point of view on it and how I felt about it for [her]
I think what happens
I'm not 100 percent certain
I don't know it if becomes that easy to qualify
I don't know that for certain
I just corroborated everything that [she] had to say
I guess it was his business right?
I guess, as part of the procedure
I guess it was part of the procedure for me not to be there, right?
I felt like I was away for hours on end, right?
I was just in the bedroom and my wife was in the kitchen, but I didn't eavesdrop or anything like that
I just turned the TV on very loud
I didn't know if it was the right thing to do, or if it was the wrong thing to do
I certainly hope that you're going to make some very good use of this.

Landon's uncertainty can be heard throughout this I-poem, even in the repetition of words "think" and "guess." He noted an uncertainty in his role related to the screening processes and in his comfort with how the process unfolded.

Other participants described the weight they carried in feeling that it was their job to help prove that their loved one indeed qualified for MAiD. For example, Deborah explained that "you second-guess everything," and she described the tension of having to prove that her husband was certain of his decision, while holding her own sense of uncertainty. Participants described how they felt they were sharing this burden of proof with their loved one, required by the processes and procedures related to MAiD. The sense of control offered by MAiD was shadowed by the lack of control available to participants and their loved ones in terms of gaining eligibility. Assessors decide, based on written criteria, if and when someone is eligible, and this added a heavy burden to family members and their loved one. Sandra described her experience saying:

> The fact that it was so new certainly added to the anxiety in the beginning . . . I do think everyone was treading carefully. But, once we had the date, I never doubted that they would come through. The Palliative Care doctor who was to administer

> the medication lived an hour away from here – an hour and a quarter away – so he called several times over the long weekend just to talk and to make sure that [my husband] hadn't changed his mind, and that he was still going to be able to give consent at the end, which was very much being followed to the letter. And he was warned by all three doctors who came to do the assessment that he would have to ask for assistance with his death with his last words. And that was a huge concern because there were times that he didn't have a voice – or a physical voice – because of the Parkinson's. And I know they're more relaxed about that now but they weren't at all relaxed then.

Sandra's anxiety was heightened as a result of the "hurdles" she and her husband faced regarding his eligibility. Having new and untested processes and procedures surrounding MAiD at the time of her husband death "added a great deal to my anxiety." She explained:

> Part of it was that, instead of only two assessments – which was the written criteria – they were . . . the doctor was uncertain enough that he wanted the former family physician to also do an assessment. And I felt that [my husband] had to prove to – *I* felt; this was my personal feeling – that he had to prove to each of the three doctors that he was qualified to have assistance in his death. And, in my mind, seeing what it took out of him, I felt he had to beg it wasn't an easy thing . . . it wasn't an easy decision to reach, either for the patient or for the assessors, I think. And, if I had to come down on one side or the other, I would say he actually . . . it was more like begging than applying.

Reflecting on her and her husband's experience, Sandra hoped her experience would be different than future recipients of MAiD, saying:

> for the general population, it will become a choice at the end-of-life, just like you can perhaps choose whether you die in hospital or in your own home or by your own hand in the garage or the barn or the orchard, or whatever. And I hope that it's presented as such, and that the application process will become less onerous. Because they're asking a great deal of people who are ready to die, who are weak and ill and often medicated and dying, to have to prove it to people doing the assessment.

Though she spoke of the added weight for the "people who are ready to die," for Sandra, having to help her husband prove his eligibility added a burden to her shoulders.

To summarize the surrendering and letting go voice, while assistance in dying

offered a sense a control, participants also described additional burdens they experienced as a result of MAiD. The finality of MAiD, along with the approaching timeline, added pressure. Knowing that MAiD could provide opportunity for closure and goodbyes meant that some family members experienced regret or uncertainty regarding their own sense of closure with their loved one. Others explained that the procedures surrounding the eligibility process left little room for their own emotion and uncertainty. Throughout these four voices of witnessing, caregiving, honouring choice and supporting dignity, and surrendering and letting go, family members can be seen navigating the complexities of their relationship to themselves as well as their relationship to their loved one. The tensions, harmonies, and, at times, dissonance can be understood as the subject and the countersubject move together, through the various participants' experiences. In a fugue, the exposition is deemed complete once the subject and countersubject have been introduced in each of the voices. This marks the transition to the development section.

The Development Section: Modulating Experience through Relationship with Others

In the development section of a fugue, episodes serve to transition between keys, to provide variety, and to move the subject through various keys. In this case, episodes will explore how relationship with others, including the experience of stigma, influences or modulates how family members experience MAiD. The impact of these relationships will be presented in four episodes: (a) role in family, (b) healthcare team, (c) support and accompaniment from friends, and (d) stigma, secrecy and isolation. Throughout these episodes, the motifs described above as the subject, relationship to self, and the countersubject, relationship to loved one, can be still heard.

Episode 1: Role in family. Thus far this chapter has offered many examples of family relations, and here the reader is reminded of some of these. Unsurprisingly, the role individuals held in their family impacted how participants themselves experienced MAiD. For example, Jeoffrey described how his felt need to explain his wife's physical decline to her family members who did not live nearby added weight to his final months with his wife. In a sense, he became a gatekeeper, taking on the role of protector by managing who and how his wife's family members would interact with her. He felt his experience of living with her in the midst of such suffering was unique and was not something her family appreciated or understood. The impact of this is evident when he described with frustration her family's decision to have dinner together in a nearby restaurant immediately prior to her death. To him, this was inconsiderate of his needs and his wife's needs in those final hours.

Megan's role in her family was to be consoler and peacemaker. Early on in her father's diagnosis, she felt that her job was to help her family members get through this. She described her efforts to advocate for her mother and her attempts to help her siblings and her mom come to terms with her father's decision to receive MAiD, going against their previously held beliefs. The following I-poem describes the impact her family context had on her before, during, and after MAiD.

Holding His Hand

I think it would have been good if we had planned beforehand who was going to sit where, who was going to hold what hand, you know, because it just kind of happened
I had Dad's left hand
I was holding Dad's left hand in my left hand
I had a very sore spot
I was like, "Okay, I was distracted by sister rubbing the sore spot on my back, and I

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don't want to hurt her feelings"
I was like, "I don't want to be distracted while I'm holding Dad's hand and watching him go,"
I just went, "That hurts. Please stop"
I was like, "Argh, I did it; I offended her"
I'm like, "It's stupid for me to be thinking this when my Dad is dying"
I'm like, "Well, this is my Dad dying, too"
I did offend her, but I really just wanted to focus on Dad's hand
I mean I would want someone to hold my hand if I was old and afraid and dying
I mean, honestly, some people have been like, "Why are you even in touch with your family?"
But I never could do that, and mostly because of my Mom
I'm holding his hand
I was just caretaking other people that day for sure
I remember him saying, "I'm the firstborn. I'm sorry, guys, but I really want to hold Dad's right now"
I was like, "Okay"
I just remember . . . I think the only my-needs-getting-met stuff was my husband
The only thing I remember that was just for me was, when we were walking out, there was a tree out in the field nearby that was covered with really soft green moss
I don't know why
I just ran up to it
I just sort of cleaned my hands on it because it felt like I had just held this gross process in my hand
I was holding Dad's left hand, and that was the arm that they injected things in
I watched his hand turn a different colour
I just was like, "I have to wipe this off on a tree. Sorry tree"
I just had to touch something alive
I was kind of, in my own weird idiosyncratic way, taking care of myself
I felt like I had nothing . . . like, It was not for me

As they continued to grieve her father's death, Megan negotiated how to care for her family, while caring for herself.

Tabitha described her role as protector. Aware of the pain that their mother's death brought her husband's boys, Tabitha took great care to include them in the process as much as possible. She described her efforts to protect them by advocating that her husband not die at home. She requested a family meeting, in order to help the boys feel that their questions were being answered. She described her carefulness in not wanting to

be seen as "running the show" but also acknowledged her belief that someone needed to be in charge. Each of these participants demonstrated how their experience of MAiD was informed by their role in their family and the unique family context in which MAiD occurred.

Episode 2: Relationship with the healthcare team. Along with one's role in their family, participants described the impact of interactions with healthcare team members on their experience of MAiD. Participants described a variety of experiences with healthcare providers throughout their loved one's MAiD process, with several emphasizing their appreciation of the detailed explanation provided by the physician. For example, Landon stated:

> I thought [it was] a very meaningful process how it was explained by the doctor, actually. He thoroughly explained what would happen, and that there would be no pain – and there wasn't any pain. He was a very, very nice doctor . . . so soft-spoken; he was very gentle . . . Yeah, and he was very thorough – well, he had to be thorough – during the screening process.

In this way, the physician's attention to detail and protocol helped Landon trust the processes around MAiD and actually eased his anxiety.

In a similar way, Sandra described how she benefited from the support she felt from the site manager at the nursing home her husband was being cared for until his death. She explained:

> The nursing home administrator was absolutely fantastic. She just took over all the details, and she started coming down to [my husband's] room every day and telling us; and he finally said, "It's too much information. I just can't handle it. I just want it over with; you deal with [her]." So every night before I left – or, every night before she left – I would stop at her desk and we would talk about anything that went on during the day, just the practicalities of needing to get the [IV started] and needing the medication picked up. And the doctor had wanted to collect it himself because he wanted to make sure it was the right medication. And, you know, everyone else took the load, and I really had nothing to do except to spend the time with [him] . . . Yes, we had an incredibly supportive team.

Sandra remembered with great detail how the physicians interacted with her prior to, during, and after her husband received MAiD. She recalled:

> They came over and hugged me and said they had to wait 30 minutes and come back and check for a heartbeat, and offered to bring my children – my two sons and my daughter-in-law – in, and told me to just ring the bell if I wanted anything. And they waited until my children arrived and they shook hands with them and hugged my daughter-in-law – were very respectful – told them, also, if I needed anything, to ring the bell. And they left us alone for 30 minutes and came back and checked for a heartbeat . . . And both doctors told me and told my sons, if I had any problems at all, we were to call one of them – [they] just made themselves available. And they expressed their condolences and left, and we just stayed with [him] until the undertaker came. I had made him a quilt while I was sitting at his bedside, and it was on his bed when he died, and we wrapped him in this quilt. So when he was wheeled out, we walked out with him when the undertaker arrived, and several of the staff walked out with us. And the nursing home was just tremendously respectful and supportive all the way along.

In these ways, Sandra's experience illustrates the profound ways in which the administrative support and the kindness of staff can offset the stress and intensity of the MAiD process.

Megan recalled the initial relief she felt when she heard that a social worker had been included in her father's care team, once he began pursuing MAiD. She recalled:

> When he was reaching out to find out about MAiD, someone . . . assigned a social worker to him who met with him to discuss his options, basically, and to find out a bit more about the family situation and that kind of stuff. And, at the time, I remember being really hopeful . . . about the social worker being involved, but I didn't really meddle with it; I just hoped that they would use her for that resource—or that Mom would . . . But [family concerns] never really came up, and . . . I don't think the social worker was told any of that extraneous stuff; it was just like, "Okay, how do we see Dad to his death" kind of thing.

This example shows how family members looked to the healthcare team for support and guidance in times of stress and uncertainty. Unfortunately, in this case, the social worker's assessment did not involve significant consideration of family concerns. The impact of this for Megan will be discussed further in the recapitulation. Each of these

examples highlight the way in which healthcare providers were involved in their loved one's death and how their involvement influenced family members' experience of MAiD.

Episode 3: Support and accompaniment from friends. Beyond the impact of other family members and healthcare providers, participants also described supportive relationships that gave them the sense that they were being accompanied, as they in turn accompanied their loved one. Megan noted, for example, that although her husband was not allowed in the room during MAiD, for fear of the appearance of favoritism amongst siblings, having him nearby offered her a great sense of support. She described how her priest offering prayers for the dead and her friends sending her a care package made her feel less alone. In a similar way, Tabitha described how having her sister present at the time of her husband's death was her way of being cared for. She explained:

> He wanted his sister, who he was close with, and she needed her partner there. And I said, "I need my sister there, because, at the end of the day, you all get to go home with yours, and I don't . . . I need somebody."

Jeoffrey described how his friend offered meaningful support to him in the events leading up to and after his wife's death. He told of his decision to ask his friend to help him pack up his wife's room at hospice:

> the next morning, my best friend came here at 9:30, and we drove over to the hospice, and he helped me. I didn't really need his help; I mean it was just some knickknacks, and a couple of bagsful of clothes. She didn't have a lot there, except the toiletries. But he was just with me so I didn't have to do it alone. And then, from there, we went out for breakfast and, you know, sort of I was back here at noon, and he helped me unload the car.

After being encouraged by his wife to have someone drive him home after the procedure, Jeoffrey explained how again he reached out to his friend:

> You know, of course, there's a side of me, "Well, I'm a man; I can handle it," but I'm going, "Well, you don't know much how you're going to handle this because this is . . . this is uncharted waters," right . . . and I call my best buddy, who just

> happens to be retired now, so, you know, he's got lots of free time. And he's somewhat like me; he's quite calm and, you know . . . so I called him – and I'd already called him the day before, and asked him about helping me with the hospice, right – he said, "Oh, by all means, [name], whatever you need, I'm there . . ." And he is one that, all through the journey was, "If you need [to bring her] down to a cancer appointment, and you can't go, you call me, I'm there" . . . So I explained the situation, I said, "Do you mind coming down with me? You can go across the street and have a beer, or whatever. I'll buy you a beer. Like, I don't want you in the room with us, but I just . . ." And he said, "No, no, no, you are not driving home. It's not happening." . . . And when I told [my wife] that [he] was coming, she was thrilled. She said, "I'm glad. I don't want you to be alone."

Jeoffrey explained that after the procedure was over:

> I pulled out my phone to text him that I was done, and he just happened to look over, and he's like, "I'll be right there" . . . and [my friend] came across the street and walked with me – he took the wheelchair, actually – and he just quickly asked me, he said, "Are you okay?" And I said, "Yeah." He said, "Was it all right?" And I said, "Yeah, it was peaceful; it was beautiful, and it's what she wanted, right."

Though the events leading up to, during, and after MAiD, Jeoffrey's friend accompanied him by offering practical and emotional support. Knowing what pushing the empty wheelchair had meant for Jeoffrey, the efforts of his friend to push the wheelchair for him take greater meaning.

For many of the participants, the memorials, funerals, and celebrations of life offered great support and comfort. The following quote demonstrates how sharing memories of her husband with family and friends offered comfort to Deborah in her grief:

> Usually, you know, people at a funeral come and go, and they are kind of a revolving door. But we had it set up like a program. So my oldest son was the MC, and we had a list of speakers who wanted to say something, and so we did. And then, you know, it went on; I mean I can't remember now the hour . . . I mean it was, like, 1:00 to 3:30 or something, but we were pushed for time because people wanted to talk about him. And then, of course, they wanted to eat. He would have loved it. So we got all these people there, and they were just so full of him. You know, it was just beautiful to hear people talk about him and to, you know, just come up and greet me and tell me some story about him or how much they loved him or what he had done to change their lives. It was . . . oh, I just wish he had heard it all. That would have been lovely, but I think he knew it,

> anyway, but . . . it was a fabulous day and it was exactly what he would have wanted. Yeah, it was very cool.

For each of these participants, their experience of accompanying their loved one was impacted by the support and accompaniment offered to them by family and friends.

Episode 4: Stigma, secrecy and isolation. While relationships with family, staff, and friends offered support to participants, their experience of MAiD was also impacted by stigma, secrecy, and an increased sense of isolation. Deborah pointed to this when she admitted:

> most people don't know that he chose it, and I don't tell them. You know, to me, it's not important; it's important that he has died, and he's had this impact on all these lives. But how he died is kind of immaterial.

Megan described how being involved with MAiD led her to remove herself from her regular social supports, including her church community. She described:

> I felt soiled; I felt like I didn't . . . and not just the previous stuff, but even the MAID stuff, I felt like that was an experience that had soiled me, and that I couldn't . . . I didn't want to let people in to that dark place, basically. So it was very isolating for me.

A need to protect the reputation or image of one's loved one, other family members, or oneself led some participants to use caution in sharing their experience of MAiD. Sandra described her initial uncertainty regarding telling her husband's story:

> I did not know what people might think. There are nineteen houses on my street, and about half of the people are Roman Catholic; and I did wondered how that might be received by them, but I needed have worried. I have had two people who have not approved of what I have done; I think they did not approve of what [he] had done, either, but what I did in talking about it was even worse. So one person has told that she is not impressed by my behavior, and the other one has just sort of turned her back on me. Of all the feedback I've had, there's been two people who have provided negative feedback. So, in the beginning, I did worry; I even, when I went out—because I live in a small town; I've lived here all my life—and people would stop me, and always, I would think, you know, "Is this going to be positive or negative? Just steel yourself, it may be negative." And it never was, so

> now . . . I think it's far enough behind me that I don't even think it's going to be negative; if it is, I can handle it. I understand that we don't all feel the same.

Having experienced these fears of how others might respond, Sandra felt that her task is to work to decrease the stigma surrounding MAiD. She hoped, "if everyone talks about it, I mean just think about where we could be; there would be no need to keep it quiet." Her comfort in talking about her husband's death has grown over time. This is demonstrated in one of final interview remarks, when she stated, "I don't need to remain anonymous; I'm way past that. I have no problems if you want to make anything . . . associate anything with me."

This experience is slightly different from that of Tabitha's. Tabitha and her children were not sure about telling others about her husband's choice for MAiD, but she decided to do so anyways, because it is what her husband would have wanted. In her words:

> I talk about it because [my husband] wanted everybody to know about this . . . and that it is an option . . . and it is a good option if you've got the guts to go ahead and do it . . . No, and he advocated . . . for mental illness too . . . He sought and got help as much as he could; he was on medication; he put together groups at [the local] Hospital . . . He really did want mental illness to be out there, people aware . . . and same with MAID . . . Because the kids were like, "Oh, you're going to tell people?" He said, "Yeah . . . definitely, definitely." So, and many people have asked me, "So what was it like?" I say, "It was beautiful." That's all I can say, "It was beautiful."

For Tabitha, sharing her husband's story has become her way of continuing her husband's work of advocacy. In each of these cases, participants demonstrate a careful navigation in sharing their experience with MAiD, noting the various contexts that may be more or less welcoming to their loved one's decision, and their own role in their loved one's death. To varying degrees, stigma, secrecy, and isolation impacted the experience of participants. Through these four episodes, the complexity of interactions and relationships with family

members, healthcare providers, and friends is noted, impacting and modulating the experience of participants in relation to their loved one's death.

Recapitulation and Coda: Insights from Family Members in Relation to MAiD

In a fugue, the recapitulation features a return to the tonic key and a concluding statement of the subject and countersubject, with some variation in the voices. The coda presents the final announcement of the subject, and it uses either previously heard material or new material to end the piece. While the coda offers an ending, it is worth noting, especially in context to the findings presented in this chapter, fugues do not always resolve or may actually resolve in a different key than the tonic. J. S. Bach is known to have often utilized the *tierce de Picardie* ("tierce de Picardie," 2011) to raise the third of a final chord in a minor fugue in order to have it end in a major key. In the case of exploring how family members experience MAiD, there is not a major resolution in the data. Rather, the stories of these seven participants offer healthcare providers a widened perspective on the tensions, negotiations, and considerations of family members whose loved one has received MAiD. In this recapitulation and coda section I will therefore explore how MAiD is a unique experience for family members, as well as what family members found to be most helpful in their MAiD journey and what they experienced as less helpful. Insights from family members for healthcare providers will serve as a conclusion and will lay the foundation for discussion of these findings in Chapter Five.

MAiD as a unique experience for family members. The examples provided thus far in this chapter reveal that MAiD was a unique experience for family members, requiring careful considerations by healthcare providers before, during, and after death.

For some family members, the practicalities and logistics surrounding MAiD caused them to have to think through their actions differently than if their loved one had had a non-MAiD death. For example, in several cases family members were moved from where they were receiving care to a facility that permitted MAiD. As noted above in the example of Jeoffrey's wife, this uprooting for the procedure itself resulted in additional planning to make the appropriate arrangements for travel time and transportation after the event. Leaving the hospice to prepare for their drive to the city, Jeoffrey described the simple but thought-provoking realization he had when he realized he did not know how to dress for the occasion:

> I came home about 2:00, I showered, I changed. And, now . . . well, there's a different scenario to itself. This isn't a funeral, this is . . . so it's like, "What do you wear?" . . . "Do you put a shirt and tie on?" Anyhow, I ended up just wearing dress pants and a collared shirt, right – semi-casual, semi-cleaned up.

Given that the experiences described by these participants all occurred in the first two years of MAiD in Canada, it is necessary to consider how the newness of the legislation and the accompanying policies and procedures may have impacted family members. In these early days, Landon recognized the potential for an over-emphasis on the medical aspects MAiD, saying:

> Well, you know, MAID's new, right. It's like, you know, I still think it's like uncharted waters, right . . . And I think . . . you have to handle the psychological side of it very well, actually, right. You know, like . . . I know there's medical stuff involved with MAID, right, but you have to put a human aspect into it.

Similarly, the newness of MAiD added a great deal of pressure and anxiety to her and her husband as they navigated rigid eligibility criteria required at that time. She recalled, "everyone was so tentative and following the criteria to the letter – and more, if they had to – because everyone was a bit afraid of litigation and didn't want to do anything to have

the process in front of a court." In these ways, the newness of MAiD forced an emphasis by providers on following the correct steps and processes; this overemphasis on the medical and the procedural seemed to impact the experience for patients and family members negatively.

Because MAiD is in its early days, multiple family members emphasized their concern that still today, many people may not be aware of it. Several participants described how they did not learn about MAiD until their loved one was already deemed palliative. David explained how for him and his wife, it was not until they were in the hospital that they first learned about MAiD. He says, "one of the weird things about this is, it's all so new, and it's a service that you might want, but you don't know about it. Therefore, you don't ask for it."

The time following MAiD also presented a unique experience to family members. The following I-poem shows Sandra's reflections on how her grief might be impacted by MAiD.

Grief After MAiD

I kind of wonder sometimes if the grieving process is the same for people who've been on the MAiD journey?
I don't really know
I don't feel like I fit in either field
I think I didn't have the horror of having to find [him] dead when I came in from shopping . . .
I'm still not quite sure just where I fit in there
I have no regrets
I have flashbacks from time to time, but they're never of [him] dying
I think I supported him
I certainly would choose that route for myself if I were in a position to do so
I'm healthy now
I don't have any expectation of needing it in the near future
I certainly want to see it open and natural and an option—an end-of-life option
I think that, as it becomes more normal and more talked about, there won't be this separation of the grieving process
I think I won't feel that people are looking at me and thinking that, "Basically, [he]

committed suicide"
I know he did . . . in a technical way
I think that as it becomes a more common procedure, that everything about it will stop being in its own little world
I mean just think about where we could be; there would be no need to keep it quiet

In terms of shared grief, the time after MAiD had implications for family relationships. For example, Megan recognized how much the relational context of her family contributed to her experience of MAiD and how much MAiD contributed to her family's ongoing relational context. She explained, "So there's, like, ramifications of what happened around Dad's death still going on today . . . But, not so much about his death itself, but just our family dynamics around it." In this example it appears that how MAiD occurred, and what context relationally it occurred in, impacted the long-term experience of family members.

Participants highlighted that MAiD was a unique experience and presented distinct opportunities and challenges to family members before, during, and after MAiD. Given these experiences, family members also identified what was most helpful and what was least helpful to them during their experience. These insights point to implications for healthcare providers as they continue to support patients and family members through this challenging time.

What was helpful. All participants offered insights about what was most helpful to them about the procedure and processes surrounding MAiD, including the thoroughness of explanation provided by physicians or the presence and availability of healthcare providers. Four aspects identified as particularly helpful included: practical help in preparing for MAiD, availability of knowledgeable supports prior to MAiD,

assistance with planning and anticipating needs for the patient and family member(s), and opportunity for storytelling.

Practical help included assistance with caregiving and logistics. Several participants described the process of becoming eligible as onerous and believed it added uncertainty and anxiety to an already difficult time. As mentioned above, Sandra experienced this burden of proving her husband's eligibility:

> The thing that was the most helpful – the person that was the most helpful – would have been the site manager at the nursing home, who sort of badgered people for answers and dates and times, and just . . . I'm not sure I would have done as much on my own, partly because I would have been more likely to accept what I was told, and partly because I just didn't have the energy to chase anymore. But somebody else was doing that, and I could give my energy to [my husband] and try and make his final days as reasonable as possible.

In this case, the site manager's attention to detail and persistence in planning allowed Sandra to focus her energy on her husband.

Though Megan struggled to pinpoint any positive details of her father's death, she commented on the setting selected for MAiD:

> here's something nice about it—the windows. It was nice that we had windows looking out at nature; that was good. If it had been in a room with no windows, I think that would have been very claustrophobic. And it was nice that it wasn't as clinical-feeling, I guess; because it felt like a room, with a kind of a living room aspect to it. So that was good.

Though her family were given few options regarding where MAiD would occur, other than the family home, the more home-like feel was appreciated by Megan.

Some participants found the planning process associated with MAiD to be helpful, thinking proactively through potential challenges and needs that might arise. For example, family members were able to voice their preference about where MAiD would take place, with several of them asking their loved one to not receive MAiD in their

family home. Others were able to voice who they needed to have with them during and immediately after their loved one died. Not feeling rushed, and having time to plan and make decisions together, was also helpful. David summarized:

> I think the most important thing for us is that the whole thing was done as a process . . . I keep saying that . . . Life is a process, and death is a process. And we weren't rushed or . . . everything was explained to us. It was done at a leisurely pace, if you will. We were . . . [she] was able to deal with all the details, like, of her own events, so she felt it was hers. And she wanted it to be a celebration – and it truly was. And it saved me – I didn't have to phone everybody and say, you know . . . The most important people were there and they told other people; I never had to do that. I can't think of anything that should be done differently, honestly, from our point of view.

Many participants noticed an increase in caregiving support once their loved one was deemed to be palliative. Though in many cases this care could have been beneficial earlier on, participants noted that this support meant that loved ones could focus more on their relationship with their loved one, as they approached death. For Tabitha, she recalled how the chaplain at the hospice was part of the family meeting that she requested and how his advice was helpful for her husband's boys, especially considering the fact that they had lost their mother suddenly years prior. Tabitha described the chaplain as an "ally" and recalled, "His advice to the boys was, 'Take the time. Your Dad's still here. Spend that time with your Dad."

Along with offering practical support, participants were also grateful to those caregivers who made themselves available. Sandra recalled the comfort that she felt as a result of her husband's physician's availability:

> Well, I had come home; it was 9:00 at night – I had just spent 12 hours at the nursing home – and the call was on my answering machine at home. And the doctor – whom we had met – was a Palliative Care doctor and absolutely wonderful, and he said, "I want you to call me day or night if you have any questions. And I know that the questions don't come up during office hours."

> Which just, you know, took away so much anxiety and concern; I mean, obviously, I never called him, but just knowing I could.

In addition to these tangible acts of care before and during MAiD, perhaps most helpful was the opportunity to tell their loved one's story after their death. Many participants spoke of how the opportunity to write their story, or to tell their story helped them process the events for themselves. Even in participating with the interview process for this study, participants noted that reflecting on their loved one was helpful to them. Participants believed storytelling was "therapeutic" and important to their own grief. For example, Landon explained that, "it's a way of not bottling things up inside of you. You know, you're sharing your story, right; you're sharing your grief, right; it's out there, right. You're not really bottling it, you know, inside of you." He also took comfort in the fact that those who knew his wife felt she would be proud of the story he had written. For Deborah, storytelling provided a means to bring her husband closer. She explained:

> I mean it's something . . . it's kind of a cold comfort, I guess, in a way, but it kind of brings him closer . . . hearing, like, telling the story again, and talking about how he was and who he was. It just makes it a little bit more . . . . Yeah, it's a little more significant.

Beyond these personal benefits of storytelling, Sandra took comfort in the potential impact that her husband's story had on others in similar situations:

> all of this is happening because [my husband's] story was told. So, to me, that makes this worthwhile. It means that it's hard for me to leave it behind and move on. But I'm not sure where I would move to, having spent 10 years of caregiving and not having any independent life. I think that telling . . . talking about it, whether it's writing or with interviews or . . . I was asked by the [Province] Health Authority to do the presentation. I think that that's helping other people avoid either a long, painful, drawn-out death or, in a couple of cases – in two cases, possibly – lonely, silent suicide. So I feel there is some value in telling this story . . . I feel I had his permission. I know we've touched a lot of people, just from the messages and the phone calls and the letters and the emails, and people stopping me on the street.

Here Sandra noted that "we've" touched a lot people, suggesting that telling their story after her husband's death has been a joint venture shared with her husband.

The following I-poem demonstrates how storytelling offered participants a means to reflect, to remember, to grieve, to advocate for others in similar situations, to feel closer to one's loved one, and to honour one's loved one.

Afterwards

I was offered support by Dying With Dignity Canada
I did have some of my friends also suggest that I see a bereavement counsellor as well
I didn't, actually
I just felt I had to handle it on my own, right.
I could still reach out at any moment
I thought that sharing [her] story was actually good
I don't know
I guess, therapy for me, actually
I actually approached a radio station
I spoke
I tried to send emails
I almost got on the air
I went
I approached
"I'm going to write the story"
I put in 3,500 words
I got published
I sent my story
I got a little eight- or- nine- minute blurb
I was very, very nervous
I did get a lot of feedback
I'm not usually . . .
I'm not a very creative person
I'm more of an analytical-type person, right
I just felt to do it right . . .
I felt very creative
I usually go to bed at 10:00
I couldn't sleep
I woke up
I brought my laptop
I started the story
I wrote most of it in one night.
I, come 4:00 or 4:30, I was all finished.
I still have trouble, to this day, reading it, you know. It just gets me in the heart
I get goosebumps

I think it's important to share your stories

As described earlier, for several participants, their willingness to share their loved one's story grew over time, mirroring in a sense their own bereavement. For many, storytelling seemed to have been their way of coping with the stigma, secrecy, and isolation mentioned in Episode 4. These aspects of practical support, availability, participation in planning, and opportunity for storytelling all proved helpful to participants.

What was less helpful. In contrast to these helpful aspects, areas identified by family members as less helpful included lack of support in preparations for MAiD, uncertainty around eligibility criteria, and inadequate or inaccessible aftercare supports. While some participants found the information and interpretation of the eligibility criteria for MAiD and the process itself to be helpful in making them feel informed and prepared, several participants felt that a lack of these added anxiety and uncertainty to their experience.

As previously described, family members had to advocate for their loved one, their family members, and their own needs. For example, Tabitha noted that she had to organize their family meeting with the healthcare team, pointing to the fact that it had not been offered prior to her requesting it. In hindsight, Megan believed her family would have benefited from a family meeting. She explained:

> I imagine that it would be more helpful if there was some sort of meeting . . . perhaps a meeting with anyone who's going to witness it, just to go over, "This is what a death might look like," for whoever's . . . like, because, even the death rattle thing just completely threw Mom. And, you know, just to let them know that they're . . . I don't know, I don't want to say "normalize it" – that's not quite right – but to maybe make it less scary, less unknown, and maybe to give a chance for the people who are going to experience it together to talk about it together . . . like, if you're going to experience it as a group, maybe to talk about it as a group beforehand; and maybe even have a game plan, like, say who's going to sit where,

> who's going to hold what hand. Because those are the things that turned out to be very important, sad memories later, "That Mom didn't get to hold his hand. Mom didn't get to have a last kiss." So maybe some sort of information / planning meeting.

With more attention to these family dynamics and their group experience, Megan stated, "I think that would have mitigated some of the long-term sadness, especially for Mom." In terms of the actual event of MAiD, Megan noted that, again, her family was not prepared for how it would unfold. She explained:

> in the time since then, I've often thought, "Would it have been good if [the nurse] had turned to all of us and said, 'Has everybody said what they wanted to say?'?" . . . Or something like that, because [my brother], afterwards, was like, "Oh, there was so much I wanted to . . ." you know, like, he just . . . but, in the moment, like, when she said, "So, is it time?" like, Mom says that she didn't realize that meant, "Injection." She just thought, "Okay, we're getting ready for the injection now." So, for Mom, when the injection started, she wasn't even really fully onboard yet. So, then Dad became unconscious, and there could not be a last kiss, and like, you know . . . so, for Mom, it was devastating . . . But I don't think that [the nurse] was actually rushing . . . well, I guess it depends on how you look at it. In a sense, I felt like we were . . . you know, they kept checking, like, "Okay, is it time?" you know. So it felt a little rushed, but it wasn't done in a hasty manner, is what I mean.

Given the felt urgency leading up to and during MAiD itself, and the relational challenges facing her family, increased support specifically assisting the family in preparing for her father's death would have been helpful. This scenario stands in stark contrast to David's story, mentioned above, in which he described the slow-moving process of preparing for MAiD as a family, over time.

It is clear from participants that both "before-care" and "after-care" were important to family members. Megan reflected that a "check-in" with the family after their loved one died might be helpful, though she emphasized that the "preparatory stuff" would be the most important thing:

> because I think that we just sort of blundered into it. I mean Dad had his whole thing planned, but I think we were just like, "Wah," you know, because you do, you go kind of squirrely. It's such a weird experience. And, in retrospect, you go, "Oh, I would have done this differently.

This experience stands in contrast with that of David, who shared how valuable the before- and after-care was for him and his wife:

> We had counselling when we were in Palliative Care, which helped us to talk to one another, you know. I mean not that we did not; we were quite open with one another, which is good. But the thing is, that we didn't know about Palliative Care; we didn't know about death; we didn't know what we were in, you know. So we had counseling along with Palliative Care, which is . . . they help you understand your . . . myself being a primary caregiver; it helped [my wife] to accept me in that role, all those different things. Well, that . . . and, of course, it helped us anticipate the dying, you know . . . I think we had counseling about two weeks before [she] made the decision . . . .

Noting that ultimately the decision for MAiD was made by David and his wife, without any interference from the counsellor, David went on to explain how having the same counsellor visit him after his wife's death was also helpful:

> But about two or three weeks afterwards, a counselor did sit down with me here, and I think we had about three visits . . . But our counselor knew [my wife], you know, and knew . . . she had participated with us as a couple. So when she came to see me when I was alone, she knew us as a couple, and she knew [my wife], and I did not have to go through anything like that, you know . . . . It was done beautifully; it was just done beautifully.

This contrast in the before- and after-care provided to these participants is something that healthcare providers must consider.

Participants' insights point to the importance of healthcare providers being available and providing information related to MAiD and palliative care early on. According to the participants, efforts should be made to not rush the process, and before-care services including counselling should be offered to families. In addition to these preparations, intentional after-care supports, which take into consideration the familial

and relational context, would be helpful to family members. These supports could include creating opportunities for storytelling. With an awareness of how MAiD may present family members with unique challenges and opportunities, and with these insights from family members regarding what was most helpful and what was less helpful in their own experience of having a loved one receive MAiD, healthcare providers can better support family members in this time of loss. Implications for practice will be expanded upon in both Chapter Five and Chapter Six.

Summary of Research Questions

The purpose of this thesis has been to understand how family members experience MAiD. Data was analyzed to address the four research questions put forward in Chapter One. The first question asked was: How do family members describe being involved with MAiD? Family members described their involvement in various ways. As highlighted in the voices of witnessing and caregiving, many participants emphasized their role as caregiver, noting the intensity of responsibilities that grew as their loved one's illness progressed. Some described being a part of the decision-making process for their loved one, though many highlighted that they were strictly in a supportive role and were not in any way trying to influence their loved one's end-of-life decisions. Participants talked about the time they spent with their loved one in their final days. This involved bearing witness to their suffering, providing physical and emotional support to their loved one, advocating for their loved one's eligibility to receive MAiD, and making necessary arrangements for both MAiD and for the funeral/memorial. Family members often acted as a liaison between family members, their loved one, and the healthcare team. Some emphasized their felt responsibility to continue to advocate for MAiD after their loved

one had died, and others focused on sharing their loved one's story and honouring the life of their loved one. In these ways, participants demonstrated the unique ways they were involved in a complex process.

The second research question guiding this study was: How are family members' values and beliefs acknowledged or integrated into the process or experience of MAiD? Family members noted a tension felt in trying to honour the values and beliefs of their loved one, while attuning to their own experience and needs. This complexity was highlighted in the relationships between the subject and countersubject in the fugue—one's relationship to themselves, and one's relationship to their loved one. This integration of self into one's care for another was also described in the voices of honouring choice and supporting dignity, and surrendering and letting go. Some participants spoke of how their beliefs around MAiD changed over time and as the result of bearing witness to the profound suffering of their loved one. For some, MAiD aligned with their personal beliefs and values. For others, there was a felt incongruence between their loved one's decision and their own religious beliefs and personal values. Many participants described how they willingly surrendered their own needs or desires to support their loved one. Some cautioned that MAiD was about the individual who was dying and that family member beliefs and values should not influence end-of-life decisions. Others felt that the entire process was not at all about them, and they wish now that they had been more honest about their needs in the time leading up to, during, and after MAiD. The policies and procedures surrounding MAiD, as described by family members, tended to focus on the consent and certainty of the person receiving MAiD, and this resulted in family members feeling it was their responsibility to corroborate their

loved one's responses and emphasize their wishes. In several cases, this added stress to family members. Some family members highlighted how helpful family meetings were prior to MAiD, while others mentioned how they believed such a meeting would have been helpful in their own situation. As is seen in these findings, careful attention to how family members' beliefs and values are welcomed or not welcomed into policies and procedures related to MAiD is one area that calls for further attention by policy-makers and MAiD assessors and administrators.

The third question put forward was: How do individuals find or make meaning in their loss of a family member who received MAiD and how does this evolve over time? Family members found meaning in their loss in various ways. Many found that having opportunity to say goodbye and to plan the final moments with their loved one brought them meaning. Similar to other end-of-life scenarios, participants felt that having opportunity to be present with and care for their loved one until their final moments was meaningful. Many found that telling their loved one's story after they had died was helpful in providing opportunity to remember their loved one and to honour their loved one's life. The opportunity to tell their loved one's story served to reduce their experience of stigma and social isolation. Storytelling allowed them to feel understood. For some, however, their faith communities and social context made it difficult to share openly about their loved one's decision to receive MAiD or about their involvement and experience with MAiD. While this study did not specifically look at the grief experience, aspects of grief were present in the data including anticipatory grief, the importance and helpfulness of saying "goodbye," and the role of aftercare supports for family members in

this particular situation. Further research is needed to better understand the impact of MAiD on family members' grief over time.

The final research question put forward in Chapter One was: What insights do family members have for healthcare providers involved in MAiD, and what are the implications for nurses? Family members had various insights for healthcare providers, as described in the recapitulation and coda in Chapter Four. General insights from family members included a caution to remember the emotional or "psychological" side of MAiD and to not only focus on medical aspects. Some family members felt there was an overemphasis on the procedural aspects of MAiD. They noted that this added an unnecessary burden on them as caregivers. Family members appreciated having thorough explanations of end-of-life options early on, which acknowledged their loved one's physical reality. They also appreciated time with loved ones to "get on the same page" and experience MAiD as a process, as opposed to an event. Facilitated family meetings were helpful for some. Others expressed how a family meeting with those who would be present at their loved one's death could have potentially mitigated some of the complex relational issues that arose as a result of unexpected circumstances occurring in their loved one's final moments. Practical help with physical caregiving and planning logistical aspects of MAiD allowed family members to focus on their loved one. Several family members highlighted how exhausted and burnt-out they felt after carrying the caregiving role independently until the very end. They suggested that respite services and caregiving assistance could be beneficial to patients and family members much earlier on in the illness journey. Family members also felt that grief support and aftercare services tailored to those whose loved one has received MAiD would be beneficial. These helpful

insights from family members are further incorporated into the discussion of findings that follows in Chapter Five, leading to implications and recommendations for nursing practice.

Chapter Summary

In conclusion, with attention to how participants in this study relate to themselves individually and to their loved one, listeners can hear and honour the complexity experienced by family members whose loved one has received MAiD. These findings reveal how these relationships to self and loved one were negotiated by family members as they witnessed the suffering of their loved one, cared for their loved one, honoured their loved one's choice while supporting dignity, and ultimately surrendered to the realities that accompanied MAiD. The unique experiences represented in these four voices reflect the complexities faced by family members; they must integrate their own self, their relationship to their loved one, and their relationships to others, as heard in the episodes. By listening to these voices, nurses and other healthcare providers can learn from the experiences of family members and honour the tensions presented in the data. The result is a contrapuntal fugue—full of harmonies, dissonances, silences, nuances, modulations, unresolvedness, and even beauty.

CHAPTER FIVE: DISCUSSION OF FINDINGS

Using the structure and style of a fugue, the findings presented in the previous chapter draw attention to the varied experiences of family members whose loved one has received MAiD and to the diverse factors impacting these experiences. In this discussion of findings, the broader healthcare context in Canada, in which MAiD is situated, will be explored, providing the background needed to better understand how these particular contextual factors impact the way in which MAID is carried out across Canada. As described in Chapter One, the policies, procedures, and processes surrounding MAiD are located both within the biomedical model as well as within the palliative care philosophy, creating a noteworthy tension with implications for how family members may experience their loved one receiving MAiD. By examining MAiD through the lens of both of these approaches to healthcare, the complex experiences described by participants in Chapter Four are better understood.

A critical examination of these conflicting models raises the question of how current approaches to MAiD value the social bonds and relationships of patients. It also gives clarity to the tensions described through the subject and countersubject, and through the various voices highlighted in the findings. Given how participants described their experience of MAiD, the findings from this study suggest that a stronger, thicker view of relationality, consistent with a palliative approach, could strengthen the processes and procedures surrounding MAiD. Relational ethics offers such an approach, moving beyond a weaker form of relationality, which focuses care on the individual, to a stronger relationality that better values the relational context of patients, or *persons.* Resulting

considerations for healthcare providers, family members, and patients who receive MAiD are presented.

This study's findings add to the emerging literature since 2018 in Canada on family members' experience of MAiD. As explained in Chapter Two, the literature as a whole, to some extent, answers the research questions driving this thesis. In the literature, family members described various forms of involvement in the process and experience of assisted death. Values and beliefs of family members were acknowledged and integrated to varying degrees. The effects of assisted dying on family members' grief and meaning making experience were varied, and researchers offered several helpful insights from family members for health care providers involved. Throughout the literature, assisted dying presented families with opportunities and burdens. This thesis adds to the recent research conducted in Canada, in that it represents a sample beyond the urban centres of Vancouver and Toronto, and it includes family members with a broad range of perspectives toward MAiD. Moving beyond content analysis, this study offers a more theorized interpretation of the experience of family members and incorporates the diverse range of values and beliefs of participants in a more nuanced way. In light of these findings, the remainder of this chapter explores some of the more salient themes for deeper discussion.

The Impact of Biomedicine on Family Member Experience

Drawing on the metaphor of the fugue used in Chapter Four, the subject and countersubject emphasize the tension felt by family members as they navigate their relationship to self and their relationship to their loved one. The development section of the fugue highlights ways in which one's relationship to others—to family members,

healthcare providers, and broader social and religious forces—influences how participants experienced the death of their loved one. As discussed in Chapter Two, given the newness of MAiD in Canada, minimal research exploring the experience of family members has been conducted to date. Globally, there remains little evidence to draw upon in relation to this study's findings. Therefore, the context of MAiD in Canada, both socially and in healthcare, will form the backbone of this discussion. As described in Chapter One, MAiD is situated in both a biomedical model and a palliative care philosophy. Biomedicine, with its emphasis on the individual, stands in tension with palliative care, which seeks to emphasize the whole person. These seemingly contradictory approaches to care provide insight into how family members experience their loved one receiving MAiD. The context of MAiD, as described in this study's findings, is one that has relied heavily on the biomedical model of medicine.

Mind-body Dualism in Biomedicine

Biomedicine, or modern medicine, rose at the time of the Enlightenment, with its emphasis on rational ways of knowing (Naidoo & Wills, 2016). With a scientific-reductionist foundation, biomedicine is based on objective measures, resulting in a conceptualization of the body as mechanistic—some *thing* that follows predictable laws and that can, with skillful intervention, be fixed (Naidoo & Wills, 2016). An overemphasis on treatment and cure has had repercussions for how care is provided, even today. According to Hinshaw (2013), since cure is the end goal of medicine in this model, "the ultimate health problem in Biomedicine is death" (p. 18). In this model, then, MAiD becomes the ultimate cure—offering a treatment even for death. In the findings, participants described watching their loved one lose control over their body and mind, in

a sense losing the battle they had being fighting against their illness. As one loses control, they are placed into an adversarial relationship to their body or at least in relation to their illness. Both patients and their family members sensed the inevitability of approaching death, and they recognized MAiD as a way to control that inevitability. In a way, MAiD became the best choice after "fail[ing] medical treatment" (Hinshaw, 2013, p. 22). The outworking of the biomedical model tends toward mind-body dualism, an intolerance for suffering, a resistance to meaning-making, and a prioritization of autonomy and individualism as values in society and in healthcare. Findings in this study suggest that this model does impact the experience of family members.

With mind-body dualism, non-biological aspects of a person's experience are valued to a lesser degree. The cognitive and emotional are seen as separate entities, with objective data being prioritized over subjective data. Evidence of the continued effects of this mind-body dualism, or disrupted embodiment, show up in the findings in two different ways. First, participants described the uncertainty they felt in evaluating if their loved one was "really living" as they watched them become dependent on others for basic needs or live in fear of losing cognitive function. When their loved one's mind and body were fully-functioning, family members perceived their loved one to still be true in their essence as a person; losing either of these capacities, however, risked a loved one's humanity, personhood, and sense of self. Many participants expressed their belief that their loved one's dignity was kept intact because of MAiD; their loved one had died without ever losing physical or cognitive function. MAiD offered a way to preserve the loved one in their true form before a physical and/or cognitive decline could interfere. Besides providing a way to end their loved one's suffering, the ability to preserve the

physical integrity and cognitive ability of their loved one was, for multiple participants, a means to justify their loved one's decision to receive MAiD.

Related to mind-body dualism, the second way disrupted embodiment was evidenced in the findings was the degree to which participants embodied their emotions. Throughout the findings, family members prioritized their rational responses over their emotional reactions. For example, when confessing her "moments of doubt," Deborah explained, "but I mean that's emotional response." She emphasized the facts that she knew, and she placed her emotions secondary to her rational conclusions. In the I-poems there is a predominance of statements related to thinking and knowing, with many fewer I-statements connected to feelings or emotions. Family members acknowledged having both feelings and thoughts, but they believed it was their thoughts that should be trusted, and enacted, even at the expense of their emotions. Sandra described how "it tears you apart; it tore me apart." She recalls:

> with one side of my face, with one-half of your heart and your being, you're providing physical and emotional care and the necessities of daily living; and with the other half, you're listening and sort of agreeing that, "This may be the best option that he has."

When describing her caregiving burden, she described how there was neither "emotional space" nor "headspace," again demonstrating these two distinct aspects of her experience. It was not until after her father's death, and after receiving significant counselling support, that Megan was able to work through the disrupted embodiment she experienced in conjunction with her father receiving MAiD. At this point she realized she could be angry with someone and still love them. In other words, she could maintain her thoughts and opinions, and she could still feel a complex range of emotion. Unfortunately, for

many participants, their experience of MAiD pointed more to a disrupted embodiment, with a strong separation of thought and feeling.

Throughout the findings participants noted that policies and procedures surrounding MAiD focused heavily on the patient's eligibility, in terms of physical symptoms, diagnosis and prognosis, consent, and certainty of their decision to receive MAiD. In the descriptions of doubt and internal tension felt by family members in relation to their loved one's decision to receive MAiD, there was a common reliance on the certainty of their loved ones' decision. By watching their loved one maintain their position for MAiD over time, family members could compartmentalize their own emotions, focus on what they knew, and rest in the best rational choice they could make to support their loved one. Unfortunately, for many participants, this meant setting aside their emotions to be dealt with at a later time. This emphasis on the objective and the rational is consistent with the biomedical model of care.

Suffering and Meaning-making in Biomedicine

Another consequence of biomedicine that is closely related to mind-body dualism is an intolerance for suffering at an individual, collective, and societal level. This, along with a resistance to meaning-making, was heard and felt in several participants' experiences. While all family members vividly described the incredible suffering they bore witness to, participants responded to this suffering and engaged in meaning-making to varying degrees. Tensions can be felt throughout the four voices, as participants juggled their feelings of helplessness with their need to support their loved one. They recalled the impact of watching their loved one lose meaning in their life. Several described their loved one's process of pursuing MAiD as meaningful, though none

emphasized attempts to find meaning in the midst of their loved one's suffering. When describing conversations with members of the healthcare team prior to MAiD, no participants described any care provider asking them what mattered to them or attempting to ascertain potential meaning behind their illness or suffering.

As described in Chapter One, meaning-making in the midst of suffering can provide opportunity for the ill patient to resist the generalizations characteristic of modern medicine (Frank, 2013). According to Frank (2013), in a postmodern, post-colonial medical model, the ill person takes on the responsibility of discovering what their illness means in their life. Though no explicit question was asked of participants regarding how their loved one made meaning in their suffering, it is worth noting that participants did not describe their loved one as pursuing meaning-making, nor did they highlight attempts of the healthcare team to assist in this process. Many participants shared that their loved one chose MAiD as a means to avoid suffering and to welcome death. Though one of the participants described MAiD more as a means to accept the inevitable reality of approaching death, this acceptance emphasized an acceptance of mortality, more so than an acceptance of suffering. One of the main aims of MAiD is that it provides a means to avoid or end suffering. For the loved ones of participants in this study, it offered a sense of control in a time where there appeared to be little room for human agency. It provided an alternative to enduring suffering. In this way, the descriptions of MAiD given by participants highlight an approach to suffering consistent with biomedicine's aim to treat and cure.

Hinshaw (2013) argued that in biomedicine, suffering, or the meaning of that suffering for an individual, can be overlooked or ignored. He explained:

> Suffering involves a symptom or symptoms that threaten the integrity of the patient as a person. The meaning that a given symptom has for the individual patient defines the nature of the suffering experienced . . . Failure to recognize and treat suffering is often a reflection of the inability of the caregiver to focus on the person rather than the disease. (Hinshaw, 2013, p. 59)

When this meaning of symptoms or suffering for the patient is not considered by healthcare professionals, the person is not seen as a whole, but rather as a body to be treated and cured. If patients are not encouraged to seek meaning in their illness or suffering, this can also contribute to disrupted embodiment. As seen in the findings, Landon provided a warning to this end: "you have to handle the psychological side of it very well, actually, right . . . I know there's medical stuff involved with MAID, right, but you have to put a human aspect into it."

Autonomy and Individualism in Biomedicine

Another outworking of the biomedical model evident in this study's findings is the emphasis on autonomy and individualism. As noted in Chapter One, our approach to healthcare and to death and dying has largely been focused on the individuals' autonomy (Canadian Nurses Association, 2015). This emphasis was seen in the findings, as family members described the processes and procedures surrounding MAiD as being very much focused on their loved one. Family members were not asked how they felt about MAiD, and several felt this omission was necessary, in order to protect the autonomy and individual choice of the person requesting MAiD. When making decisions about the timing of MAiD, family members relied on their loved one to "make the call" and saw themselves as supportive figures. In these ways, evidence of biomedicine, with its emphasis on the individual, shapes how family members experience MAiD.

Relationality and Biomedicine

Given the discussion this far, it is clear that biomedicine has influenced how MAiD is carried out across Canada. The aim of this discussion has not been to argue that biomedicine is inappropriate to healthcare, but rather to uncover how its philosophical roots and everyday practices may inadvertently and negatively impact family members' experience of MAID, when it neglects relationality. With a recognition of the potential that biomedicine has to perpetuate mind-body dualism, foster an intolerance of suffering and a resistance to meaning-making, and idealize autonomy and individualism as primary values, the following section outlines how a relational approach to healthcare, more consistent with a palliative care philosophy, might strengthen MAiD-related practices. An approach that values a strengthened relationality may improve the experience of MAiD for family members.

Autonomy in Relationship

In their description of the principles of bioethics, Rodney, Burgess, Phillips, et al. (2013) defined autonomy as, "an observation about human nature and morality, with an ethical imperative drawn from it. The observation about human nature is that human beings *have the ability to act voluntarily, based on information*" (Rodney, Burgess, Phillips, et al., 2013, p. 67). They noted, "for individuals to claim—and fully realize—their fundamental human rights, they must be able to autonomously act to engage with their rights and the responsibility that accompanies each human right (Rodney, Burgess, Phillips, et al., 2013, p. 67). The doctrine of informed consent has its roots in the principle of respect for autonomy (Rodney, Burgess, Phillips, et al., 2013). Though healthcare professionals have a significant role in respecting individual autonomy

through the process of informed consent, Rodney, Burgess, Phillips, et al. emphasized that this informed consent "*should* be a reflection of continuing communication, collaboration, and commitment" (p. 68). The emphasis of autonomy should be on relationship in combination with opportunity for patients to reflect on and express their interests, all in light of ongoing information sharing about various available options. It should not be "a one-time evaluation of information and a decision about how to proceed" (Rodney, Burgess, Phillips, et al., 2013, p. 68).

Reflecting on these aspects of ongoing communication, collaboration, and commitment, Rodney, Burgess, Phillips, et al. (2013) noted that these have not been the emphases of the traditional bioethical approach. They explained that instead, the approach has focused "on the role of healthcare professionals in relation to individual, rational patients" (Rodney, Burgess, Phillips, et al., 2013, p. 68). They noted that "this leaves us with little insight into the role of emotion, or power imbalances in patient—professional relationships. It also leaves us with little insight into the role of family or community in decision making" (Rodney, Burgess, Phillips, et al., 2013, pp. 68-69). The CNA (2015) echoed these concerns when they recognize that:

> Our approach to death and dying in healthcare has been excessively rationalistic and that end-of-life care decision-making has been excessively individualistic, with too much emphasis on autonomy instead of caring, family solidarity, love, mutual respect and attentiveness. (p. 21)

As Murray and Jennings (2005) explained, "The law, ethics and policy, must come to grips with the fundamental communal public—not private—issues of mortality and meaning" (p. 21). With a continued emphasis on the individual patient, we are left with little insight into the role or experience of family members in relation to MAiD. In their systematic mixed study review, Roest et al. (2019) noted that "euthanasia decision-

making is typically framed in the patient-physician dyad, while a patient-physician-family triad seems more appropriate to describe what happens in clinical practice" (p. 1).

In reflection of the impact of this principle-oriented approach to healthcare ethics, Rodney, Burgess, Phillips, et al. (2013) cautioned that serious concerns have been raised about its adequacy over the past two decades. They noted that some of these concerns may be related more to how the principles have been used, as opposed to theoretical limitations in the principles themselves. They explained:

> In the hands of busy clinicians, educators, and even ethicists, there has been a tendency to employ them in a non-contextual and reductionist manner. For instance, in applying the principle of autonomy to a dying patient's request not to have his family told of his prognosis, the discussion might quickly centre around whether he was competent, informed, and unconstrained, with little exploration of the meaning behind his request, his understanding of his own and his family's grief processes, the values he held about his family's well-being, and so on. The principle of autonomy, despite its rich theoretical traditions, can too easily be reduced to binary equations (competent/incompetent; informed/uninformed; constrained/unconstrained) if not handled with careful reflection and good clinical insight. (Rodney, Burgess, Phillips, et al., 2013, p. 72)

Based on this study's findings, my interpretation of the data suggests that in an effort to ensure a close following of the law, procedures and policies surrounding MAiD have leaned toward these binary equations, at the expense of a richer approach that involves family members and invites exploration of meaning behind requests for MAiD.

Noting the limitations of principlism, Rodney, Burgess, Phillips, et al. (2013), highlighted the "tendency for bioethical principles to place an undue emphasis on the moral minimum of obligations while largely ignoring characters and personal dispositions for their influence on moral deliberation and action" (p. 73). Drawing on this study's findings, the above examples show that in many cases, the procedures around MAiD emphasized "the moral minimum of obligations" (Rodney, Burgess, Phillips, et

al., 2013, p. 73). The question remains, in addition to these obligations, were other factors considered as part of this process? Roest et al. (2019) hoped that by exploring the involvement of family members in assisted dying and by working to understand their experience, a new perspective might "challenge the underlying ethical-legal framework, which is based on the patient-physician dyad and the related concepts of autonomy and the relief of suffering" (p. 18). Perhaps an approach that considers procedural aspects as well as existential concerns, such as the meaning behind requests for MAiD, family experience of grief, and individual and family values, could help healthcare providers move beyond "the moral minimum of obligations" (Rodney, Burgess, Phillips, et al., 2013, p. 73). In several of the participants' experiences, procedural aspects and existential concerns were both addressed. These experiences were marked by participants' increased involvement and satisfaction with the MAiD process.

Viewing Patients as Relational Beings: Person-Centred Palliative Care

An integrative approach that considers procedural and existential concerns could involve a more explicit integration of palliative care. Belgium scholars echoed Rodney, Burgess, Phillips, et al.'s (2013) sentiments when they identified three major threats of euthanasia: legalism and proceduralism, euthanasia following its own course, and instrumentalization (Vanden Berghe, Mullie, Desmet, & Huysmans, 2018). They note that these are all at odds with the spirit of palliative care. The danger of legalism, they said, is "when people think that meeting those legal conditions is in itself a sufficient condition for good care" (Vanden Berghe et al., 2018, p. 74). In other words, good care must always encompass more than simply meeting legal and procedural requirements. If euthanasia follows its own course, they argued, it may move further away from mainstream health-

and end-of-life care, creating what Vanden Berge et al. described as a "twin-track policy" (p. 76) in end-of-life care. This twin-track policy could result in little genuine dialogue and poor bedside collaboration between professionals supporting euthanasia and those supporting regular palliative care. Finally, the danger of instrumentalization of death is that people may begin to view euthanasia as an instrument to end difficult life processes, rather than letting these life processes follow their course. This could result in a trend where the dying process in general is increasingly considered to be "undignified, useless and meaningless, even if it happens peacefully, comfortably and with professional support" (Vanden Berge et al., 2018, p. 77). Vanden Berge et al. feared that these three major concerns could further disconnect euthanasia from palliative care. They clarified their position stating:

> According to the WHO definition of palliative care (WHO, 2016), palliative care should not intend to hasten death. Therefore, euthanasia cannot be part of palliative care. However, we think that euthanasia and palliative care can occasionally be considered together when caring for one and the same patient. (Vanden Berge et al., 2018, p. 71)

Noting the polarization in end-of-life care in Belgium, Vanden Berge et al. suggested that palliative care, including the involvement of multidisciplinary team members who are well qualified to practice end-of-life care, may in fact serve euthanasia.

In their exploration of person-centred care dialectics in the context of palliative care, Öhlén et al. (2017) noted that person-centredness remains conceptually ambiguous, living in tension between more dominant individually oriented approaches and the more recent population-level approaches. It also sits in tension with individualization and standardization. Recognizing these tensions, Öhlén et al. suggested that person-centred care calls healthcare providers to "understand the person and their personal narratives:

their circumstances and biographies" (p. 5). With person-centred care, "Yes, the person is an individual. And, yes, the person is always more than an individual" (D. Klaassen, personal communication, December 13, 2019). This approach allows person-centred care to move beyond an individualistic or micro level focus to recognize the person as being socially and societally contextualized.

For Öhlén et al. (2017), person-centred care:

> is an ethical stance, which gives prominence to both suffering and capability of the individual as a person. The dialectic analysis points towards the importance of extending person-centred care to encompass population and societal perspectives and thereby avoiding a problematic tendency of affiliating person-centred care with exclusively individualistic perspectives. (p. 1)

With a recognition of micro, meso, and macro implications for person-centred care, this approach can move healthcare providers toward "people-centred" care. Drawing on this term used by WHO (2013), Öhlén et al. noted the importance of both person-centred and people-centred care "pointing to care focused and organized out of needs and expectations of people and communities, and not out of disease and biomedical aspects per se" (p. 6).

Looking closely at the dynamics around MAiD as shown in the findings, the power in these relationships seems to rest on the guiding principles legislated and closely followed by practitioners across the country. Because these have been formed in the name of person- or patient-centred care, and with the aim of promoting autonomy for patients at the end-of-life, these policies and procedures hold a great deal of power in how MAiD is carried out. Is it possible that while attempting to protect patient autonomy, the current application of the principles and processes is actually perpetuating what Rusthoven (2014) described as "a false autonomy"? As Donchin (2000) explained:

> Any tenable conception of personal autonomy is bound to be subject-centred; but a *social* conception that is relational in this stronger sense will take into account the need for a network of personal relationships to develop and sustain competencies necessary to act as self-determining, responsible agents. (p. 192)

Though integrating family members into processes and procedures surrounding MAiD presents challenges, doing so does not necessarily pose a threat to respecting the individual autonomy of patients.

In his book, *Relational Being,* American social psychologist Kenneth Gergen (2009) illuminated the significance of relationship, noting that in western society "we remain fundamentally estranged" (p. 6). He noted that the prevalence of loneliness is not a surprise, "if we understand ourselves as fundamentally isolated" (p. 6). Noting the distinct loss of meaning in people's lives observed by therapists, scholars, and theologians, he pointed to society's celebration of autonomy or the "self-made man" as the possible cause of this loss. Gergen queried:

> When asked about what is truly meaningful to them, many people speak of love, family, and God. Yet, what is the origin of such investments? Could they ever be discovered in solitary? What if we could understand all that we call thought, fantasy, or desire as originating in relationships? Even when physically isolated we might discover remnants of relationship. We would invite a renewed appreciation of self *with* others. (p. 7)

According to Gergen (2009), if one believes that the bounded self is truly the fundamental atom of society, one must maintain a necessary caution about connection. If the self is primary, relationships become secondary, and the demands, expectations, and obligations of these relationships will threaten individual freedom. Offering an alternative view, Gergen explored what happens if we consider ourselves to be relational beings, rather than bounded beings. "Through co-action we come into being as individual identities, but the process remains forever incomplete" (Gergen, 2009, p. 44). He went on

to explain that as relational beings, "We do not own what we say or do" (Gergen, 2009, p. 45). We are transformed through the continuing process of co-action, with relationships unfolding without our control.

Gergen's (2009) argument for considering ourselves as relational beings, rather than bounded beings, does not negate the significance of honouring individual identity; rather it allows for a transformative co-action. Looking to the findings, perhaps this transformative co-action is best demonstrated in David's experience, where he and his family were able to take nine months to process together the decision his wife made for MAiD. In this case, both his wife's wishes as well as the needs of her loved ones were honoured. This transformative co-action is similar to Sherwin's (1998) definition of relational autonomy that describes "a capacity of skill that is developed (and constrained) by social circumstances. It is exercised within relationships and social structures that jointly help to shape the individual while also affect others' responses to her efforts at autonomy" (as cited in Rodney et al., 2013, p. 93).

When considering this transformative co-action in light of end-of-life care, Roest et al. (2019) acknowledged the major ethical issue in determining whose rights should prevail, or carry the most weight, especially when multiple, competing needs are expressed. Roest et al. warned "about the importance of family dynamics and interpersonal influences in assisted suicide, whether it is medically assisted or not, and how that could infringe on the patient's responsibility and choice" (p. 17). Their literature review highlights the "tangle of needs, experiences and responsibilities of patients, their families and physicians" (Roest et al., 2019, p. 17). Because of this dynamic, Roest et al. argued that:

> Situating autonomy and the relief of suffering in the patient-physician-family triad, instead of the patient-physician dyad, draws the attention to specific ethical questions. One of these questions is how a voluntary request for EAS should be both enabled and safeguarded when family members are closely involved in the process of EAS decision-making. The concept of relational autonomy could help examine the different links between relationality and autonomous choice for EAS. Reciprocal and collaborative aspects of autonomy might come into play in EAS, due to the possibility of choice and planning that is typical of assisted dying in contrast to a natural death. (p. 17)

In defining strong relational autonomy Donchin (2000) explained its two interlocking components of reciprocity and collaboration. She explained:

> Strong relational autonomy is reciprocal in two respects: (1) it is not solely an individual enterprise but involves a dynamic balance among interdependent people who are engaged in overlapping projects and (2) the self-determining self exists *fundamentally* in relation to others. (Donchin, 2000, p. 191)

Collaboration, the second component of a strong relational autonomy, allows for collective discussion, in which differing perspectives can be shared, often lessening possible misunderstandings (Donchin, 2000). The implications specific to MAiD of a more relational understanding of autonomy, which allow transformative co-action, will be discussed later in the chapter.

In the findings, many participants shared how palliative care provided immense relief to both their loved one and themselves as caregivers. They noted that prior to their loved one being deemed "palliative" they were left on their own to provide care and to locate resources. Participants described various reactions to their loved one becoming palliative, with some noting that the new label brought with it a sort of reality-check of their loved one's impending death. Others experienced relief with the realization; they appreciated the opportunity for relevant conversations to occur given their clarified understanding of the situation. Though supports offered in palliative care, including case management, nursing care, home care, family meetings, social work, and spiritual care

practitioners, were appreciated and valued by all participants, these supports varied significantly. Few participants had facilitated family meetings prior to their loved one's death. Many family members struggled to locate aftercare or bereavement supports, and few were formally offered any follow-up care. Avenues for storytelling as a means to process one's grief were found outside of palliative care and through MAiD advocacy groups. As seen in several participants' narratives, MAiD was offered as an option at end-of-life, alongside palliative care services. If it is indeed under the umbrella of palliative care services, should the supports offered to patients who have chosen MAiD and their family members not be provided in a way that is consistent with a palliative approach? That is, should the processes and procedures before, during, and after MAiD not address the patient's needs, viewing the patient as a whole-person, situated within a relational context?

Given the eligibility criteria for MAiD, patients requesting the service have likely received care from a variety of Canadian healthcare services. Many of these continue to provide treatment and cure in line with the biomedical model. Multiple participants reported that it was not until their loved one was deemed palliative and they were exploring palliative care services that they became aware of the option of MAiD. In this way, MAiD finds itself situated between these two seemingly contradictory models. What has been the impact of this tension on family members? From the findings, it can be surmised that in current practices of MAiD, care largely directed toward the individual patient has resulted in family members being somewhat displaced. Currently there is a lack of involvement into decision-making processes. As so keenly pointed out by one participant, MAiD is viewed and treated as an event, rather than a process. In light of

these observations, a more relational approach, consistent with a palliative philosophy, may result in a better integration of family members into their loved one's MAiD experience. It may remind healthcare providers to view the patient as a whole person, living in a broader social context. It may help family members navigate their expressed tension between their relationship to themselves and their relationship to their loved one.

Comparing a Weak and Strong Relationality

By gaining an awareness of the significant influence the biomedical model continues to have on MAiD, it can be concluded that current MAiD practices and procedures favor what Slife (2004) referred to as *weak relationality*. He explained:

> From this weak relational perspective, persons, places, and things (as well as practices) begin and end as self-contained individualities that often take in information from the outside. Relationships and practices in this weak sense are reciprocal exchanges of information among essentially self-contained organisms . . . weak relationality, then, is ultimately a type of individualism or atomism. (Slife, 2004, p. 158)

In contrast, relationships viewed with an ontological relationality, or *strong relationality*, "are not just the interactions of what was originally nonrelational . . . . Things are not first self-contained entities and then interactive. Each thing, including each person, is first and always a nexus of relations" (Slife, 2004, p. 159). Objectivity is used with a weak relational perspective, where "objects must be abstracted from their concrete contexts, because in their fundamental realness—in their practical and concrete realities—all things are ontologically related to their context and qualitatively change as their contexts change" (Slife, 2004, p. 159). As Slife explained, in this way, all things are completely dependent upon their context.

Differentiating between a weak and strong relationality, Slife (2004) said:

> Unlike weak relationality, where essentially self-contained objects must cross time and space to influence one another through traditional cause and effect, strong relationality assumes that objects are instantaneously or even simultaneously present with other objects. They are not only influential but also constitutive of the very nature of beings or events. (p. 160)

Historically, said Slife (2004), strong relationality has been considered "unreal and unscientific" (p. 160). Biomedicine, which forces objectivity, abstractionism, and reductionism, results in a weak relationality. Drawing on Heidegger, Taylor, Toulmin, and others, Slife (2004) confirmed this, noting that "abstractionist ontologies have dominated our Western intellectual consciousness, often without recognition, for several centuries . . . [these] abstractionist frameworks are considered to be contextless, atomistic, and thin, whereas relational frameworks are contextual, holistic, and thick" (p. 164).

Based on the analysis of this study's findings, it is my conclusion that our healthcare system, and the delivery of MAiD in Canada, is largely built on abstractions with little regard for context. When we remove the patient or the person from their broader context, or relationships, we abstract them, objectify them, and practice a weak form of relationality. In keeping with the biomedical model, patients viewed this way, must be "stripped of any particulars—any rich and changeable contextual qualities as well as any intrinsic or defining relations with other objects" (Slife, 2004, p. 165). By "abstracting away from the particular" (Slife, 2004, p. 165) the theories and beliefs put forward by biomedicine, and a weak relationality, are thin. As Slife (2004) explained, with a strong relationality, all things, including all meanings, are best understood as relationally tied to other things. Because of this, "any loss of detail (and thus relations) is an impoverishment, if not a distortion, of the meanings themselves" (Slife, 2004, p. 165).

Slife clarified, "The abstractionist motto for identity is: "I am who I am regardless of who you are" (p. 166). By contrast, "the relationist motto for identity has to be contextual: 'I am who I am, in part, because of who you are'" (Slife, 2004, p. 166). In this way individual uniqueness is allowed for within a relationist identity.

This uniqueness of each individual is achieved "through a distinct nexus of relationships rather than a distinct set of beliefs and values" (Slife, 2004, p. 167). Individually-held abstract beliefs and values are important, though they are not fundamental of individual identity (Slife, 2004). Relationships are only possible when the other is "able to truly *be* 'other'" (Slife, 2004, p. 167). One's own identity, therefore, requires relationship with the other. This is also why relational ontology can maintain unity even in the midst of differences in belief. Slife (2004) explained:

> belief is not the most fundamental level of being and existence . . . . A relational ontology assumes that we are always and already community; our very nature is shared through practices and our very constitution is mutual. Community members are, of course, separable, just as parts of a whole are separable from other parts. They have their unique contribution to the community. However, our qualities—just as the qualities of all parts, are mutually constituted and contextual. (p. 168)

In this way, "the ground of relationship—shared being—is not jeopardized by disagreement" (Slife, 2004, p. 173). Given the polarizing nature of MAiD, a relational ontology that allows for difference in beliefs while maintaining connectedness could offer a hopeful approach to family members who find themselves in conflict.

Several participants emphasized that MAiD was "really not about me." They viewed MAiD as being entirely about the patient receiving it, and they saw anything other than full resonance with that individual's values and beliefs as imposing on their loved one's autonomy and individual rights. Perhaps the emphasis on consent, and "the

minimal obligations" mentioned above in the policies and procedures surrounding MAiD as seen in the data, is to prevent disagreements within families, for example, from interfering with their loved one's decision. According to Slife (2004), however, this difference of opinions, values, or beliefs, does not need to threaten the "ground of relationship" (p. 173). A move away from the abstractionist ontology emphasized by modern medicine, allows us to "no longer [be] primarily rational beings, with our minds and ideas as our only or even our primary resources" (Slife, 2004, p. 174). Instead, as contextual beings with inbuilt relational resources, conflicts can "be engaged rather than avoided, otherness can be valued rather than feared, and community can truly be a unity of diversity" (Slife, 2004, p. 174).

As relational beings, the suffering witnessed by family members can also become an opportunity for understanding to be generated. As Hinshaw (2013) explained, "There are aspects of the self known only by others. Persons acquire their personhood within community, in connection with other persons" (p. 52). Casell (2004) wrote, "Suffering exists, and often can only be understood, in the context of others" (p. 34). Modern medicine has limited the concept of responsibility, including the responsibility of the ill person (Frank, 2013). Frank (2013) explained, "Persons live *for* others because their own lives as humans require living that way. The self is understood as coming to be human in relation to others, and the self can only continue to be human by living *for* the Other" (p. 16).

With a stronger relationality, or a relational ontology, family members would be viewed as integral to any discussion surrounding end-of-life. Difference of beliefs and values amongst caregivers, family members, and the patient themselves would not have

to be avoided, silenced, or feared. All members of the team, including family members and the patient, would share responsibility to the others. As Rusthoven (2014) stated, "The caregiver-patient relationship is bidirectional. The caregiver has always had the duty of care but patients may have duties to the caregiver as well" (p. 215). Agreeing with James Nelson, Rusthoven (2014) cautioned against "moral immunity" for patients, recognizing that "the contemporary emphasis on patient autonomy and uncoerced decision-making may wrongly translate patient vulnerability into freedom from obligations and duties" (p. 215).

Mayeroff (2013) defined caring as "helping another grow and actualize himself [*sic*], [it] is a process, a way of relating to someone that involves development" (pp. 1—2). He explained that caring has a way of ordering a caregiver's values and activities. In caring, Mayeroff stated, "I experience what I care for (a person, an ideal, an idea), as an extension of myself and at the same time as something separate from me that I respect in its own right" (p. 7) This care does not give the caregiver power over the recipient of care, but rather it creates a shared trust, "as if I had been entrusted with the care of the other in a way that is the antithesis of possessing and manipulating it as I please" (Mayeroff, 2013, p. 9). Researchers in Belgium noted that in their experience:

> the provision of care at the end of life results in the greatest satisfaction when patient's families, proxies and informal caregivers are involved as partners in the process. In Flanders this is commonly called "autonomy in relationship" (*autonomie in verbondenheid):* close relatives do not obstruct the expression of the patient's autonomy, but their involvement can help the patient clarify his/her own wishes and achieve their realization in the most comprehensive way. (Vanden Berghe et al., 2018, p. 72)

Family members take on significant caregiving roles prior to and during MAiD. As Mayerhoff (2013) implied, this caregiving relationship, or shared trust, has the

potential to honour both the patient and the family member. A social and relational understanding of MAiD allows space for multidirectional relationships to exist, perhaps creating an environment where family members can be both caregivers and care-receivers. While recognizing patient vulnerability and seeking to honour a patient's wishes and needs, might we also broaden our understanding of care such that we need not ignore or diminish those in relationship with the individual requesting MAiD.

Relational Ethics as a Proposition

Given the nature of the methodology used in this study, which is grounded in a feminist-narrative tradition, the Listening Guide (LG) challenges its users to listen for both context and power dynamics. A feminist perspective listens for voices that may have been silenced. It honours the complexity so evident in the stories of participants in this study. In this way, the LG moves us beyond obligation-based ethics, allowing for a multiplicity of ethical and moral values. With a feminist methodology used for data analysis, relational inquiry is used in this discussion as a means to "move [us] beyond the surface(s) of people, situations, and relationships" (Doane & Varcoe, 2013, p. 150). As Rodney, Burgess, Pauly and Phillips (2013) explained:

> relational ethics asks us to consider context at every level—from the individual through to the larger society within and between nations . . . . [it] reminds us to be reflective about our own positionality, and to embrace complexity and diversity on moving toward a moral horizon. (p. 96)

In this line of inquiry, relational ethics will be used as an illuminating structure for deeper understanding of these findings. As the contrapuntal voices were woven together in Chapter Four as a fugue, four themes of relational ethics will serve to weave together the contextual aspects of this study's findings, seeking to honour family members' relationships to others, their loved one, and themselves.

MAiD Occurs in a Relational and Moral Space

According to Bergum (2013), relational ethics is "built on the premise that all relationships as experienced are moral" (p. 127). A relational ethic is an evolving, tentative thing that expands in shared experience, never offering a "clear high mountain vantage point from which to view a situation with complete objectivity" (Bergum, 2013, p. 127). The objective, reductionist approach of biomedicine does not acknowledge the intersubjectivity highlighted in relational ethics. Bergum explained, "In a relational ethic, one is 'inescapably, dialogically, in the midst,' and it is this relational space that gives moral meaning to our actions (Gaita, 1991, 142)" (p. 127). As Jopling (2000) pointed out, relational ethics allows the other to be "absolutely foreign" (p. 153) and unique, creating something new through encounter. Drawing on Jopling (2000), Bergum (2013) summarized, "Relational space, as a moral space, is where one enacts responsiveness and responsibility not just for oneself *or* for the other, but within the space of being for and with both oneself *and* the other" (p. 128). In his article exploring the effects of requests for assisted dying on patients, physicians, and families, Kimsma (2010) suggested that often the space between physicians and patients leaves "maximum room for patient values, but it lacks space for the physician's values" (p. 361). Is it possible that the relational space between any caregiver and care-receiver has room for multiple, co-existing values?

Donchin (2000) called for a shift from an individualistic model of autonomy to a relational model. This model, she said:

> must take full account of relevant ways in which individuals and families are differently situated in relation to one another, to available resources, and to social organizations that impinge on family life. The least powerful, especially, need the

> principles protection that a carefully nuanced recognition of relational autonomy can afford and an unswerving commitment to honour it. (Donchin, 2000, p. 203).

In this way, autonomy can be extended beyond the individual, "without undermining anyone's sense of integrity" (Donchin, 2000, p. 203)

Relational ethics have been offered as a framework to guide healthcare professionals who often experience competing obligations "as they try to 'do good' within competing values, demands, and expectations" (Doane & Varcoe, 2013, p. 146). Pesut, Thorne, Greig, et al. (2019) suggested that relational ethics may help to deepen understanding regarding nurses' commitment to wraparound care. They explained:

> Relational ethics is built upon the assumption that good care can only be determined in the space between nurses and patients. This requires that nurses know patients well and connect to them as persons. This connection should be characterized by noncoercion, trust, openness, responsiveness, and appropriate boundaries. Furthermore, relational ethics takes into account how the environment affects the context of the nurse-patient relationship. (Pesut, Thorne, Greig, et al., 2019, p. 224)

This lens, Pesut, Thorne, Greig, et al. (2019) argued, provides insight into why nurses take person- and family-centred care so seriously.

In addition to looking at the relational space between healthcare providers and patients, the findings in this study also challenge us to examine the relationship between family members, who often fulfill the role of caregiver, and their loved one. Findings clearly demonstrate that family members experience competing obligations as their loved ones receive MAiD. Throughout the findings it is clear that family members are often key characters in the events surrounding MAiD, and they become caregivers, entering the moral and relational space of care. Caregiving was a dominant voice heard throughout the participants' stories. Both the opportunities and the challenges that caregiving presented to loved ones contributed to their experience of MAiD. With the recognition that family

members are very much in this relational, morally charged space, it is necessary to examine how they exist in that space and how current policies, processes, and procedures related to MAiD enhance or hinder family members' ability to meet their moral obligations. Given their significant roles in caregiving, family members may also benefit from the framework and language offered by relational ethics.

Four themes are provided by Bergum (2013) to give language to a relational ethic: environment, embodiment, mutual respect, and engagement. These relational themes provide a helpful structure for understanding the relational context family members live in before, during, and after the death of their loved one. The relationships presented in the findings that family members have to others, their loved one, and themselves can be understood in light of these relational themes. The voices heard in the data—witnessing, caregiving, honouring choice and supporting dignity, and surrendering and letting go—can be seen as expressions of these relational themes by family members. By examining these relational themes, implications for healthcare providers can be drawn for how we might better support family members to enact their moral obligations in the challenging time surrounding their loved one's death.

Relational theme 1: Environment. The first theme in relational ethics is environment. The environment, in relational ethics, is not seen as an objective, measurable object. As Bergum (2013) explained, "within the relational approach, environment is not only 'out there' to be manipulated and managed. Instead, environment is 'in here,' in each of us as a living system that changes through daily action" (p. 129). In addition to viewing ethics personally, socially, or politically, Bergum emphasized the need to view ethics as ecological. An ecological consciousness involves not only

individual caretaking but also caretaking of shared or common areas. Bergum (2013) explained, "With this kind of attention to environment, while the [patients . . .] become the primary focus, all those who care for them are involved and personally affected as well" (p. 130). Referencing Gadamer (1996/2006), Bergum (2013) stated, "ecological consciousness" includes, "not only the ability to manage by oneself (autonomy) but also the ability to manage with other people (community)" (p. 130). Community in this case is made up of autonomous individuals living in conscious relation to one another (Bergum, 2013; Irigaray, 2002). The individual is both autonomous and connected to others—respecting and sharing life accordingly (Bergum, 2013). Relational ethics encourages an awareness of one's presence in their environment. In this case, family members find themselves in a complex environment, which is often focused on their loved one's medical needs. An ecological consciousness by healthcare providers may be the first step to recognizing the presence of family members in the environment of a patient requesting MAiD, and it may challenge us to broaden our perspective to consider the effects of our care on family members.

Relational theme 2: Embodiment. The second theme in relational ethics is embodiment. As Bergum (2013) described, "Embodiment calls for healing the split between mind and body so that scientific knowledge and human compassion are given equal weight: emotion and feeling are understood to be as important to human life as physical signs and symptoms" (p. 132). It reconnects the "body as object" to the "body as lived" (Bergum, 2013, p. 132). As seen in the findings, some family members describe or enact a disrupted embodiment, emphasizing their own reliance on thoughts over feelings, for example. Others describe their loved one as "not really living" if their physical or

cognitive decline continued. Is it possible that the current emphasis on consent and meeting eligibility criteria is furthering this approach to care?

Bergum (2013) noted that it is often family members who assist professionals in becoming, or remaining, mindful of the patient's embodied reality. Working in the often objective world of medicine can cause healthcare providers to view the patient in front of them as an object or disease to be treated or cured. It is the family member of the patient who often reminds the team of their loved one's humanity, personhood, and lived reality. In the case of MAiD, is anyone reminding family members of these aspects of their loved one? Or, are family members, as caregivers, being positioned to also view their loved ones through an objective, reductionist lens?

In the findings, it was clear that several family members saw MAiD as a way to preserve the dignity of their loved one, preventing any further deterioration of their loved one's mind and/or body. As patients lose these various abilities and even the ability to make decisions or give consent for care, it is those closest to them who take up this task. In relational ethics, both the patient and the caregiver are seen as embodied, with both being affected by their connection to others. Connecting this back to the concept of autonomy, Bergum (2013) summarized:

> [One's] autonomy—their self-knowledge and responsibility—is fostered by [their] connections to others, to those who know [them] best. The lived reality of autonomy is achieved through human connections. Our relationships define who we are. The lived body is more important to the principle of autonomy than the object body as there is no autonomy for human beings in isolation from each other. Being alone and independent is primarily experienced because there are others to miss. (p. 133)

In this way, patients and caregivers are viewed as embodied and autonomous, as well as connected to others. This acknowledgment allows for the caregiver to maintain a balance

of sensitivity to another's embodied reality, be it pain or fear of loss, while being self-aware and respectful of their own distinct and separate embodiment. This perspective could aid family members in honouring their loved one's autonomy and personhood, while maintaining their own sense of embodiment.

In their systematic literature review, Gamondi et al. (2019) described the cognitive and emotional work of family members whose loved has received assisted dying, as seen in the literature. Gamondi et al. (2019) explain:

> Families had to engage cognitively and emotionally in the experiences of assisted dying to come to a decision that could reflect their values and those of the patient. Families experienced mixed feelings, and they had to cognitively process many decisions that challenged their values, belief systems and their knowledge about legal issues and procedures. (p. 10)

In this way, this study's findings confirm the tensions felt by participants in previous studies, showing the complexity of the rational and emotional experiences of MAiD.

A closely related subject of embodiment is that of suffering. As seen in the findings, witnessing a loved one's suffering was extremely difficult for participants and even led some family members to change their previously held beliefs to support their loved one in their decision for MAiD. In one case, complex relational challenges in the family contributed to a degree of collective suffering that went beyond the physical. As previously noted, biomedicine and its emphasis on autonomy has influenced society's willingness and ability to tolerate suffering. Doane and Varcoe (2013) noted that:

> within the neo-liberal dominance of Western thinking, where individualism is central and biomedicine powerful, suffering that arises from physical pathology has received greater attention. Our obligation [as nurses] to be in the difficulty also extends to examining and acting on suffering as it arises through relational dynamics. (p. 154)

Our response as healthcare providers can be to bear witness to suffering, to try to alleviate it or "fix-it," or to turn away from it. Referring to Caputo (1993), Doane and Varcoe (2013) explained:

> if one enters into nursing situations without the need to fix or make the difficulty/suffering better but rather to open, be in, witness, and be instructed by it, the difficulty/suffering can be a pathway toward meeting the relational obligations to both our patients and ourselves. (p. 154)

They noted that "there is a tendency to think of difficulty and suffering as something negative and something to be avoided. However, *difficulty is at the heart of ethically responsive nursing care"* (p. 154). According to Doane and Varcoe, one obligation of healthcare providers is to "be in difficulty" (p. 153). Given their roles, healthcare providers find themselves in close proximity to suffering, uncertainty, and conflict, and they often feel their own intense emotions, as well as those of others (Doane & Varcoe, 2013). In a similar way, as their loved one approaches death, family members are subject to this obligation. They must bear witness to their loved one's suffering.

Drawing on Caputo (1987), Doane and Varcoe (2013) described this "challenge of being in the abyss of difficulty" (p. 153) as something that is humbling and something that "both strikes us down and draws us near" (Caputo, 1987, p. 275). Caputo (1993) therefore argues for the importance of being in difficulty as it presents itself and of entering the abyss of difficulty and suffering, not to succumb or surrender but to be "instructed by the abyss, to let the abyss be, to let it play itself out" (p. 29). The implications for healthcare providers are clear: understand and assist family members to consider both difficulty and suffering "as windows into meaningful relationships and as the base for ethical-decision making and responsive . . . care" (Doane & Varcoe, 2013, p. 154). By doing this, the relational space amongst family members and their loved ones

will provide opportunity to "better understand multiple and competing obligations, goals, and perspectives; to raise questions and inquire into the particularities of each situation; and ultimately develop the clarity and courage to act in health-promoting ways" (p. 154). Again, reframing suffering beyond how the biomedical approach views it can help family members come to view their loved one's suffering in a new way, and it can assist them in their ability to care.

To summarize, embodiment may offer family members, patients, and healthcare providers a way to move beyond the potential reductionism of individualism and biomedicine. To this point, Gergen (2009) believes that properties once attributed to the individual self are in fact the outcomes of relationship. For example, he argued that reason and emotion are possessions not of individual minds but of relations. Memory, motives, intentions, and sensations of pleasure and pain are also the outcomes of relationship. Gergen (2009) stated, "All that we take to be real, true, valuable, or good finds its origins in coordinated action" (p. 31). In this way, by shifting from a dualistic mindset to a more embodied life, we move from "individual being to relational being" (Gergen, 2009, p. 32). Co-action, including co-suffering, are realities of a relational ethic. This offers agency to family members as they witness their loved one approaching death.

Relational theme 3: Mutual respect. The third theme of relational ethics is mutual respect. Bergum (2013) explained that "Mutual respect arises from the reality that people are fundamentally connected to one another" (p. 133). The challenge in healthcare, and especially in a polarized matter such as MAiD, is to maintain respect for those with differences of opinions, beliefs, values, and activities (Bergum, 2013). With attention to power dynamics, various disciplines, genders, and types of knowledge,

mutual respect requires an interactive and reciprocal approach (Bergum, 2013). Bergum explained:

> With the theme of mutual respect, we are asked to look for ways to achieve cohabitation or coexistence between people who are different but of equal worth and significance. There is a need to learn ways to engage the other, the *you,* without reducing *you*, to the same as *me,* or *me* to the same as *you.* (p. 134)

In order to foster mutual respect, Bergum (2013) emphasized the opportunity teamwork provides. Family members and the patient themselves must take on important roles in this team. From the findings, we see family members involved in the care team to varying degrees. As one participant noted, "MAiD wasn't any event; it was a sort of process." Having time for this process, and to hear from close family members and "get on the same page," was important to many participants. Several noted how helpful a family meeting with the care team was, or hypothetically would be, in facilitating this process.

Biomedicine, with its demand on patients to surrender their story (Frank, 2013), does not invite or encourage mutual respect. Bergum (2013) explained, "To reduce the other person to an object of study, or to see them as no different than oneself, avoids the problem of meeting someone who is different and makes it easier to miss the experience of 'letting ourselves be moved, questioned, modified and enriched by the other' (Irigaray, 2002, 125)" (p. 134). The question for healthcare providers remains: How do we ourselves show mutual respect to both patients and their family members, and, how do we create and facilitate opportunities for families, patients, and other members of the care team to be moved, questioned, modified, and enriched by one another?

Relational theme 4: Engagement. The fourth and final theme of relational ethics is engagement. This theme begins with an attempt to "understand the other's situation, perspective, and vulnerability. This understanding requires a true movement toward the other as a person and to genuine engagement" (Bergum, 2013, p. 134). True engagement involves person-to-person care and an entrusting of oneself to another. Referring to Taylor (1985), Bergum (2013) explained:

> It is the self-interested focus of modern life and the primacy of technological or instrumental reasoning with its search for control and domination of life and death that fragments community life and leads to general malaise or indifference to the needs of others. (p. 136)

If nursing, for example, is strictly a technical relationship, both nurses and patients become interchangeable, with both patients and professionals becoming faceless objects: patients becoming diseases or problems, and professionals becoming mechanical robots who must carry out an increasing number of duties. In the same way staff burnout could be seen as a threat to the nurse-patient relationship, could caregiver burnout amongst family members caring for their loved one at the end-of-life impact the family-patient relationship?

Engagement, as a relational theme, challenges caregivers to attend to "*this* moment, *this practitioner, this* patient, *this* place" (Bergum, 2013, p. 136). This attention offers a way to make meaning individually, through responding to one's own needs and the needs of the other (Bergum, 2013). Recognizing that the space between caregiver and patient is moral space, I would argue that the spaces between family member and patient and between healthcare provider and family members are also moral spaces. With relational ethics, these spaces position all parties to be viewed as whole persons. Drawing on Bauman (1993), Bergum (2013) summarized that "moral impulse arises because one

person elicits a response from another" (p. 136). Citing Lippitz (1990) Bergum (2013) explained:

> Engagement with others allows one to discover abilities that one did not previously know one had: "The Other enables me to do more than I can do." Such engaged relationships make it possible, not just necessary, to be moral: we gain ourselves, so to speak, and find out what we are capable of. From this point of view, engagement does not ask for *selflessness* on the part of the practitioner, as both are recognized as *whole beings*, both self-interested and other-focused. (p. 136)

In the findings, several participants suggest that acting on their own feelings would be "selfish." They saw their moral obligation as one of support and, if necessary, surrender of their own needs, concerns, beliefs, or values. Though this is admirable and demonstrates a sacrificial act of love toward their loved one, I wonder if the policies and procedures surrounding MAiD could not do more to create space for a richer engagement amongst patients, family members, and other members of the healthcare team. As Bergum (2013) noted, "With engagement, practitioners receive as well as give" (p. 137). Could this not be the same for family members?

Aware of the effects time constraints can have on engagement, Bergum (2013) distinguished between an engaged relationship that is inner rather than outer. Given the unpredictability of a patient's decline at end-of-life, or the time between their decision for MAiD and the date they receive it, there can be limitations on time for all parties involved. Drawing on Niebuhr (1963), Bergum (2013) explained how being present can lead to a "*time-full* encounter" (p. 137). In this type of encounter, the caregiver needs to attend to the moment, temporarily suspending past and future responsibilities. Participants spoke of such encounters, and of the meaning they found in being able to be with and to be present for their loved one in their final days. By being cognizant of this,

healthcare providers can again help to facilitate opportunities for family members to be fully present with their loved one, helping to create time-full moments, meaningful for both family members and their loved one, prior to MAiD. Practical applications of this may mean providing respite services earlier on for family caregivers or assisting with preparations before MAiD. As one participant recalled, "everyone else took the load, and I really had nothing to do except to spend the time with him," This support from the healthcare team allowed this participant to meet her own moral obligation to her husband in his final days and to enact the relational theme of engagement.

Enacting relational ethics through dialogue and storytelling. These four themes of environment, embodiment, mutual respect, and engagement are most easily recognized and enacted in genuine dialogue (Bergum, 2013). As Austin (2008) suggested, open dialogue is key to acknowledging fears, raising questions, and exploring solutions together (as cited in Bergum, 2013). Dialogue is not simply a part of preparation for treatment, communicating instructions, or for evaluating treatment after the case (Bergum, 2013). In the findings, much of the dialogue amongst healthcare providers focused on explanation of the procedures of MAiD, assessing eligibility criteria, and planning details surrounding the event itself. When family members were brought into these discussions, it was often to discuss the patient receiving MAiD. Bergum (2013) emphasized that dialogue "is necessary for practitioner and patient to understand together" (p. 138).

Donchin (2000) also emphasized the importance of dialogue for family members, especially in matters such as assisted dying, which hold central values for people. She noted:

> Contemporary families often involve members with diverse and, occasionally, incompatible value priorities. Respecting the decision of the dying one may conflict with a family member's sense of personal integrity. Unless survivors can discuss such qualms in a way that honor everyone's autonomy, the fabric of family cohesion may be strained to the breaking point—just when mutual support is most urgently needed. Opening differences to discussion can sustain the promise of enduring mutual connection. A gulf may be narrowed and each may catch glimpse of the other's perspective. Dialogue among those with different viewpoints may be sustained without treading on anyone's right to act as a self-determining subjects. (Donchin, 2000, p. 201)

What is effective dialogue? Jopling (2000) identified six helpful characteristics of what he refers to as a reflective dialogic encounter. First, dialogue is open to unexpected outcomes and is not goal oriented. One does not know how they will be changed through the encounter. Second, dialogue involves mutual respect, where the other is regarded as responsible and trustworthy. It requires "a willingness to encounter the other person is such a way that his or her otherness, rather than sameness or like-mindedness, is manifest" (Jopling, 2000, p. 155). Third, reflective dialogue has both addressive and responsive components. It does not simply involve exchanging information or co-creating a narrative, but rather it involves spontaneous face-to-face conversations, where both parties are present. Fourth, reflective dialogue evokes a range of other-directed emotions including care, compassion, sympathy, love, respect, shame, and desire. As Bergum (2013) summarized, "Feelings give body to words and bring back words to the body" (p. 139). Fifth, dialogue has a nominative component, which encourages mutual recognition that allows both parties to be recognized as persons through the exchange of the pronoun *you.* Finally, reflective dialogue "involves being with other persons and participating in the appropriate kinds of interlocutory, moral, and emotional relations" (Jopling, 2000, p. 156). It moves the other person from being an object of observation.

Addressing the other invites an understanding of moral and social identity (Jopling, 2000). Jopling (2000) went on to say:

> not only does dialogue open the self to itself by opening it to the other person; it is by means of reflective dialogue that persons are "talked into" knowing who they are. Interlocution is a constitutive feature of self-knowing; it is not built up from the contingent interactions of prosocial atoms. Knowing who I am is possible only in relation to other persons who constitute a community of interlocutors. (p. 157)

With relational ethics, we know ourselves as we engage with others. There is room for both relationship to self and relationship to loved one. The subject and the countersubject woven throughout this study's findings points to the complex tensions that family members navigate as their loved one prepares for and experience MAiD. Reflective dialogue with family members and patients by healthcare providers can serve to challenge the biomedical approach to care that still governs much of our healthcare today. Family members may also benefit from healthcare providers highlighting and creating space for these aspects of dialogue, both with other members of the healthcare team and with their loved one themselves.

In addition to reflective dialogue, creating avenues for storytelling is also a way in which a relational ethic could be enacted by healthcare providers working with patients and family members in relation to MAiD. Speaking of the importance of storytelling for patients themselves, Frank (2013) claimed that:

> ill people's storytelling is informed by a sense of responsibility to the commonsense world and represents one way of living *for* the other. People tell stories not just to work out their own changing identities, but also to guide others who will follow them. They seek not to provide a map that can guide others—each must create his own—but rather to witness the experience of reconstructing one's own map. Witnessing is one duty to the commonsensical and to others. The idea of telling one's story as a responsibility to the commonsense world reflects what I understand as the core morality of the postmodern. Storytelling is *for* an other just as much as it is for oneself. In the reciprocity that is storytelling, the teller offers herself as guide to the other's self-formation. The other's receipt of

> that guidance not only recognizes but *values* the teller. The moral genius of storytelling is that each, teller and listener, enters the space of the story *for* the other. Telling stories in postmodern times, and perhaps in all times, attempts to change one's own life by affecting the lives of others. (pp. 17-19)

Öhlén et al. (2017) echoed this, noting that from a person-centred perspective, healthcare providers are "informed by the application of communicative approaches to facilitate all parties to share their stories" (p. 7).

All participants in the study spoke with appreciation for the opportunity to share their story, as well as their loved one's story. They spoke of how storytelling brought their loved one closer, how it helped them feel they were still caring for their loved one, and how it was an act of honouring their loved one or carrying out their legacy. For several participants, having opportunity to write their story and have it published in newspapers, recorded on radio programs or shared at community events provided healing to their own grief, as well as means to "not bottle things up." Some participants spoke of how they gradually became more comfortable with sharing their loved one's decision to receive MAiD. Storytelling in safe environments became key to counter the isolation felt by family members, and it gave them a way to speak against the stigma they experienced having had a loved one choose MAiD. Though these opportunities provided by non-healthcare settings including Dying With Dignity Canada were appreciated by participants, they stand in stark contrast to the aftercare supports and opportunities offered by healthcare providers and the healthcare system. Few participants received any aftercare from their healthcare team, and many had to look elsewhere for support. By drawing attention to the need for dialogue and storytelling throughout the end-of-life journey, healthcare providers can assist both patients and their family members to participate in a relational ethic thereby knowing and caring for oneself and one another.

Chapter Summary

By enacting relational ethics themselves, healthcare providers can effectively redirect the current approach to MAiD, which continues to reinforce approaches to care consistent with biomedicine. Whereas biomedical models of care direct medical efforts toward individual treatment and cure, a palliative approach emphasizes whole-person care, understanding persons in their social and relational contexts. Consistent with palliative care, relational ethics may offer family members, who in many ways become caregivers, a means to enact their own moral agency in the midst of competing moral obligations in the time leading up to, during and after their loved one receives MAiD. By equipping family members to enact the themes of environment, embodiment, mutual respect, and engagement, healthcare providers can foster a stronger relationality, more in keeping with a palliative approach. This approach would have us widen our view of autonomy, to see autonomous individuals as inherently connected to one another. It would challenge our avoidance of suffering, especially at the end-of-life, encouraging meaning-making through relationship. It would cause everyone to view all persons as whole persons, moving beyond mind-body dualism, and shifting from patient-centeredness to person- and people-centeredness. Reflective dialogue and storytelling would serve to connect persons, and counter the silencing, stigma and isolation experienced by family members, while creating opportunities for grief support. In these ways, relational ethics moves the discourse of MAiD closer toward the palliative care philosophy, allowing patients, their family members, and members of their healthcare team, to know and care for themselves, while knowing and caring for one another.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

The purpose of this project was to explore how family members experience MAiD and consider implications for nursing practice. In response to the findings presented in Chapter Four, and the discussion of those findings presented in Chapter Five, in this final chapter I will present study conclusions and recommendations. A summary of findings is provided with recommendations for the various domains of nursing including nursing education, nursing research, nursing leadership and nursing ethics, health policy, and clinical practice. By examining potential implications, this chapter serves to move the stories and voices heard from this study's participants into recommendations that nurses and other healthcare professionals can consider as they care for those who receive MAiD, and their family members.

Summary of Findings

Bill C-14 passed into Canadian legislation on June 17, 2016 permitting "competent adults whose deaths are reasonably foreseeable" to receive MAiD provided their medical condition is "grievous and irremediable" and causes "enduring and intolerable suffering" (Parliament of Canada, 2016). This qualitative study aimed to examine how family members experience MAiD and consider the implications for nursing practice. Using a qualitative research methodology rooted in a feminist tradition, the *Listening Guide* (LG) was used to listen for the tensions, harmonies, and dissonances experienced by seven family members from across Canada, whose loved one received MAiD. Findings reveal that family members were involved in MAiD in varying degrees and ways. Many experienced tension in negotiating their relationship to themselves, their loved one, and others involved. These complex and varied tensions were heard in four

dominant voices throughout the study: Witnessing, caregiving, honouring choice and supporting dignity, and surrendering and letting go.

Given the problematic tendency to "affiliate person-centered care with an individualistic or micro level focus" (Öhlén et al., 2017, p. 7), procedures and policies surrounding MAiD ought to consider the relational and societal context in which it occurs. Shifting these practices to be more consistent with those of a stronger relationality and a palliative approach may improve the experience for family members. The four relational themes of environment, embodiment, mutual respect, and engagement provided by Bergum (2013), give language to a relational ethic, challenging healthcare providers to consider how they might better support family members to enact their own moral obligations in the challenging time surrounding their loved one's death. By acknowledging the social context of the patient receiving MAiD, this study extends the discourse surrounding MAiD beyond the realm of individual autonomy, suggesting a shift in care from being patient-focused, to being truly *person-centred*.

Conclusions of the Study

By listening to the interplay of voices in this study, the tensions, dissonances, and harmonies inherent in participants' voices point to the complexity of experience for family members who's loved has received MAiD. By tuning into these voices, the relationship to one's self and the relationship to one's loved one was highlighted. Various factors influencing the experience of family members were revealed and several key conclusions can be drawn:

1. Family members describe various degrees of involvement in their loved one's decision to receive MAiD. All participants described their role as caregiver,

and many experienced a lack of support in their caregiving prior to their loved one receiving MAiD. When family members did receive help, it was often after the patient had been deemed "palliative."

2. By offering patients and their family member's knowledge of the timing of one's death, participants had the opportunity to say goodbye and be intentional in their planning for both MAiD and the funeral. For some, this offered relief and was a welcomed opportunity. For others, this added anxiety and an increased sense of pressure. In families where there was relational conflict prior to MAiD, the event of MAiD itself added distress and contributed to further relational challenges. In families where MAiD was viewed as a process rather than an event, family members felt they were "on the same page" and that their experience of a carefully planned MAiD death was meaningful.
3. Family members felt that the procedures and policies surrounding MAiD were being followed very carefully. Some appreciated the thoroughness of the screening process, while others found this process to add a great deal of pressure to an already difficult situation. Though family members described their involvement in the decision-making process in varying ways, many emphasized that receiving MAiD was their loved one's decision and that their only aim was to support their loved one. The screening and eligibility procedures were focused on the patient requesting MAiD, and family members did not feel that the process was about them. The degree of certainty

expressed by the loved one choosing MAiD, influenced the degree of comfort that family members felt with their loved one's decision.

4. Though MAiD is offered under the umbrella of end-of-life options, experiences of family members in this study point to an approach to care more consistent with biomedicine, than with palliative care. This is demonstrated in the emphasis on the individual autonomy of the patient, the often delayed conversations regarding end-of-life options and realities, the exclusion of family members in decision-making and end-of-life discussions, the unbearable discomfort of family members bearing witness to profound suffering, and the lack of grief and aftercare supports currently available and accessible to family members. MAiD would look different if it was provided in a manner consistent with a palliative care philosophy.

These conclusions lead to recommendations for nursing, discussed in the following section.

Recommendations

Though this study has implications for all healthcare providers, the following recommendations are primarily directed toward a professional nursing audience. Recommendations focus on five domains of nursing including nursing education, nursing research, nursing leadership, health policy and nursing ethics, and clinical practice. Conclusions from the findings and subsequent discussion guide the recommendations, adding new insights for those working in healthcare areas related to MAiD.

Given the nature of the LG, the following statement from Nisker (2013) conveyed the challenge I hope readers will hear in response to the stories shared by these seven participants. Nisker (2013) wrote:

> For almost 20 years the wise fox's words in *The Little Prince*, 'It is only with the heart that one can see rightly' (de Saint-Exupery, 1943) has informed not only the way I engage in health ethics education, research and policy development, but also the way I live my life. I hope you will consider using story to delve deeper into the ethical issues in which we are immersed than a theories-and-principles-based approach allows. I hope you will use narratives to approximate empathy for the persons at the centre of the ethical issue, their families, and their health professionals. I hope you will use narrative to bring the beauty of persons, too often confined within a clinical diagnosis, to classrooms, conference auditoria, and policy tables. For narratives can "help compassion happen.'"(p. 120)

As recommendations are presented, it is my hope that they accurately reflect and honour the rich experiences of those willing to share for the purposes of this research.

Recommendations for Nursing Education

There are several important recommendations related to the domain of nursing education. First, nurse educators must pause to consider how concepts such as personhood, person-centredness, and autonomy are being conveyed in nursing curricula. For example, does person-centred care encompass the patient's family and social context, or does honouring autonomy simply mean upholding a patient's wishes at all costs, with little regard for others connected to that patient? Nurses need to advocate for a stronger relationality that recognizes interconnectedness as vital to being human and as foundational to being autonomous. To do so, nurses need to reflect on their own tolerance of suffering and consider how their approach to care views and values suffering as a potentially meaningful aspect of being human. Data in this study demonstrated the importance of solidarity and co-suffering—for both the patient and the caregiver. It falls

within the nurse's role to be aware of this dynamic and provide opportunities as requested, for family members to co-suffer with their loved one.

Along with this, educators must endeavor to model care that integrates family members, showing how these primary caregivers are indeed a part of the patient's care team, often for the duration of their illness journey. Data in this study reveals that current practices surrounding MAiD tend to focus on the individual receiving care. A broader view of person-centredness and autonomy, allows healthcare providers to offer relational care that does not separate the individual from their broader context. In educating nurses regarding interprofessional practice, it is vital to consider how family members provide care, and to view family caregivers as legitimate members of the healthcare team. Education toward this end can help to shift the current approach to MAiD from a model more consistent with biomedicine, to one that is more in line with a palliative approach.

This leads to the second recommendation, which is to evaluate how a palliative approach is being taught in nursing curricula. Data in this study suggests that in many cases MAiD itself is done in isolation from palliative care services. Though MAiD is viewed as an end-of-life option, in many cases, palliative care and MAiD services are seen as separate areas of service. This was noted when patients were removed from their palliative care context, and offered an entirely separate care team for the actual MAiD procedure. For multiple participants, this resulted in a separation from aftercare supports that would typically be provided to family members in palliative care. Along with this, for several participants, both palliative care and MAiD were presented as options very late in their illness journey. A palliative approach would encourage these important, challenging conversations to occur at an earlier stage in the illness journey, allowing

more time for family members and their loved ones to pursue answers to their questions and acknowledge the varying beliefs and values that may be present within a family or social unit. By educating nurses regarding a palliative approach, family members could benefit from palliative supports and informed decision-making earlier on in their care, and throughout their loved one's illness journey.

Recommendations for Nursing Research

Several significant areas for further research have emerged through this study. First, as Chapter Two revealed, there is a need for research to further explore the experience of family members whose loved one has received MAiD. In their recent systematic literature review, Gamondi et al. (2019) confirmed, "Family members' experiences in assisted dying are under-researched" (p. 13). As Rapid Response Service (2017) stated, "Acknowledgement of the experiences of family members should be an essential component of all research investigating medical assistance in dying" (p. 1). Goldberg et al. (2019) also noted, that "the clinical emphasis on patient-centred care and individual autonomy often leads to exclusion of caregivers from clinical care until patients reach the point of palliative, thus not allowing for caregiver research involvement at earlier stages" (pp. 15-16). As this is one of the first studies to look at family members' experience of MAiD in Canada, more research is needed to understand aspects of family members' experience.

The thesis findings point to further research questions including the influence of different contexts on family members' experience. As noted in the findings, contextual factors such as the location of MAiD, and the length of time from a loved one's decision to receive MAiD to the time of the actual death, have an impact. Further research is

needed to understand how these factors may influence family members' experience. Along with this, research is needed to better understand the grief experience of family members whose loved one has received MAiD, and to direct aftercare supports appropriately. Data from this study suggest that family members find themselves in between traditional grief and bereavement services, often facing stigma and social isolation. Research exploring specifically how these particular family members can be better supported in the time leading up to, during, and after their loved one's death is a necessary next step. This includes examining when and where bereavement supports are offered, especially in areas where access to MAiD may be limited requiring MAiD-seekers and their families to travel (Hales et al., 2019).

Another important area for further research is the impact of MAiD on families collectively. As Goldberg et al. (2019) argued, the majority of research to date has ignored the multiple meaningful and different relationships patients may have with their social network. Therefore, conducting research beyond the perspective of a single caregiver may provide additional insights into family member experience (Goldberg et al., 2019). Speaking of family-oriented research and practice, Baumann (2006) summarized, "the more perspectives and sources of information about a family, primarily from within the family, the better the description of that family" (p. 15). Another area for further research is exploring how the experience of MAiD may differ for family members who identify as caregivers. In this study all participants identified as caregivers, meaning findings do not differentiate between family members and family caregivers. The significance, therefore, of family members' roles as caregivers requires further exploration.

Along with these areas requiring further research, there are also research implications for nursing related to this study's methodology. The LG offers a unique lens to understand complex issues, including marginalized and understudied experiences (Gilligan, 2015). Noting its shared features with other qualitative methods, Gilligan (2015) explained how the LG goes beyond them in: "(a) attending to the first-person voice of the I and its associate stream, and (b) listening for different voices that speak to the researcher's question and tracking their interplay or counterpoint" (p. 72). The LG can also be used with quantitative approaches, "with the Guide steering the discovery phase of the research and questionnaires and statistical analysis utilized to test the hypotheses that follow" (Gilligan, 2015, p. 72). In these ways the steps of the LG offer nurse researchers:

> . . . a way of opening oneself to the experience of another that enhances the prospect of discovery . . . Before analyzing, before classifying, before thinking about what something means or trying to do anything with the data, just listen, first for the distinguishing markers or features of this particular psychological terrain, next for the first-person voice of the person speaking, and finally for the voices that speak to the question that sparked the research . . . . (Gilligan, 2015, p. 75)

As a relationally grounded profession, the LG offers nursing a research method that could well suit its wide range of scholarship, taking care to honour the perspectives and experiences of participants by remaining consistent with nursing's philosophy of care.

Recommendations for Nursing Leadership and Nursing Ethics

The findings of this study lead to several recommendations for nurse leaders. First, viewing the patient as a whole person requires a recognition of the person's context, including their family and social supports. If MAiD is being provided to a patient without appropriate supports offered to their family members, the patient, or *person,* themselves

is not being provided with ethical, true person-centred care. Data in this study suggests significant gaps both in respite services prior to an individual being accepted for palliative care, as well as in aftercare support for family members after their loved one has died. Nurse leaders must advocate for these services to become a consistent element of providing MAiD. Resources to help support family members before, during, and after MAiD, must be a priority in healthcare planning. Several participants spoke of the importance of family meetings with the healthcare team during this difficult time. Family members should not have to initiate these meetings. Nurses must advocate for these, and help to facilitate them. It is interesting to note how much of healthcare language seems to focus on the patient, including terms such as "patient care coordinator" or "patient-centred care." What happens if these terms are shifted to include the whole person—including the person's family?

In a similar way, this study challenges healthcare providers' view of family members as caregivers. Data in this study reveals that all participants saw themselves as caregivers for their loved one. Do nurses truly consider the burden of caregiving on family members, especially in the time leading up to their loved one's death? In this way, the four themes of relational ethics discussed in Chapter Five present a framework for nurses to consider how they might better equip and support family members to provide care they often desire to give. Practically, this may involve conversations with family members earlier on, discussing caregiving goals and areas of anticipated needed support, as well as providing education for family members regarding the process of dying itself. This may mean supporting family members to have difficult conversations regarding competing values and beliefs. This may mean arranging caregiving support to allow the

family to release some of their caregiving duties, creating more space and time for meaningful conversations. This may mean respecting family members as equally important members of the patient's care team. Overall, nurse leaders must keep relationality at the forefront of decision-making and organization of care.

A third recommendation for nurse leaders is to develop avenues for storytelling. Data in this study suggests that storytelling is an important aspect of the grieving process for family members whose loved one has received MAiD. It also serves to reduce the stigma and isolation noted by several participants in the findings. Though Dying With Dignity Canada has done a commendable job of creating meaningful opportunities for this storytelling to occur, healthcare providers could also help to facilitate this process, engaging with community services, including hospice societies, to serve grieving family members in this way. In these ways, nurse leaders have a significant role to play in ensuring family members are considered before, during, and after their loved one receives MAiD.

Recommendations for Health Policy

Regarding health policy, this study highlights the importance of ensuring that the procedural aspects of MAiD are not overemphasized at the expense of team-based, relational care. Data suggests that family members have not been adequately integrated into the policies and procedures surrounding MAiD. Recommendations, therefore, include ensuring that the services and approach to care found in palliative care models be integrated as much as possible into practices around MAiD. This includes ensuring appropriate resources, including a multidisciplinary team, are involved with care, and that the experience of family members is considered in all policy related to MAiD. One

example of how families ought to be considered is noted by ethicist De Bono (2017), who stated, "transfers of care for MAiD must not be onerous, nor should they impose undue hardship on patients and families" (para. 13). Recognizing the diversity of needs amongst Canadians, De Bono argued that strong partnerships amongst health authorities can ensure smooth transitions for patients and families exploring MAiD. Along with considering family members in MAiD related policy, clear communication of these policies and procedures, as well as other end-of-life options, should be offered to patients and, when possible, to their family members early on in the illness journey. When possible, the processes of presenting information about end-of-life options, screening procedures, and determining eligibility for MAiD should be done over time, ensuring that MAiD is not rushed. Policies regarding minimum aftercare supports should be implemented to ensure that these services are offered consistently to all family members. In general, those directing health policy related to MAiD and end-of-life care must remain conscious of the context in which MAiD occurs, ensuring that care for the person's grieving family members is not cut short after the patient dies.

An important challenge for policy-makers to consider is the variation of practices and regulatory clinical practice standards across the country. As Hales et al. (2019) noted, at the provincial level, Alberta is the only province to have implemented a province-wide MAiD program, meaning that much of the implementation of MAiD has fallen to individual institutions and practitioners. In much of Canada, logistics surrounding MAiD vary by province, region, city, and organization (Hales et al., 2019). Attention to potential quality gaps within the MAiD process across different contexts is essential for policy-makers to minimize negative experiences for patients and caregivers (Hales et al., 2019).

Recommendations for Clinical Practice

This study highlights several recommendations for nurses in clinical practice. As mentioned above, nurses have an important role to play in shifting individually-focused care to encompass care of the whole person. At the bedside, nurses can involve family members in caregiving responsibilities as appropriate, offering opportunity for family members to provide the care they wish to give. They can advocate for family meetings when appropriate. They can assist in planning in logistical concerns, allowing family members to simply be present with their loved one. This study points to the many opportunities nurses have to support family members in various phases, before, during, and after MAiD. Hales et al. (2019) insightfully pointed out that no literature, to date, specifically describes how to support patients and families during the 10-day period of reflection. This is one of the many unique stages of the MAiD process in which nurses can offer intentional support. Nurses can also create opportunities for conversations, dialogue, and storytelling. Recognizing the value of an interdisciplinary approach to care, nurses can advocate for access to counselling services for patients and their family members throughout the MAiD process, including grief counselling for family members after their loved one's death. Overall, nurses must remember the philosophical underpinnings of palliative care, modelling care that extends beyond the physical, to address psychosocial, spiritual, and emotional concerns.

Along with this, nurses can accept their obligation to "be in the difficulty" (Doane & Varcoe, 2013, p. 154). Nurses can enter into challenging situations with an openness to bear witness and to be instructed by the difficulties and suffering they find themselves in ((Doane & Varcoe, 2013). By doing this, suffering can be reframed as an opportunity for

meaningful relationships. In the midst of such profound suffering, this ethically responsive approach can help family members come to view their loved one's suffering in a new way, thereby supporting them in their own efforts to care. When it comes to clinical practice, nurses have a remarkable opportunity to provide care that truly honours the whole person, creating necessary room for family members to give and receive care.

Conclusion

In conclusion, this study has aimed to explore how family members experience MAiD and to consider implications for nursing practice. By using the LG, tensions, harmonies, and dissonances experienced by family members whose loved one had received MAiD were heard. Findings revealed that these experiences were complex. Given this complexity, healthcare providers ought to consider the relational context in which patients receiving MAiD exist. They ought to work to broaden their own understanding of person-centredness and autonomy to better reflect the relational aspects of care. It is my hope that this study challenges nurses and other healthcare providers to be more intentional in integrating family members into the processes and procedures surrounding MAiD, potentially improving the experience of family members while also continuing to honour the person receiving MAiD.

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APPENDIX A

Key Search Terms

Family OR relative OR child* OR spouse OR wife OR husband OR daughter OR son OR partner	AND	Experien* OR understanding OR reflect* OR perspective* OR meaning OR view	AND	("Medical Assistance in Dying" OR "MAiD" OR "Physician Assisted Death" OR "Physician Assisted Dying" OR "Euthanasia" OR "Assisted Suicide" OR "medical assistance in death" OR "aid-in-dying") **NOT** (Passive OR withdraw* n4 "life support" OR withhold* n4 "life support" OR "withhold* treatment" OR animal* OR "palliative sedation")

APPENDIX B

Limiters, Inclusion and Exclusion Criteria

Limiters
English language Peer reviewed

Initial Inclusion/Exclusion Criteria for First and Second Screening [a]

Inclusion	Exclusion
Focused on family members or relatives	Opinion pieces
Primary source materials	Articles which only discuss family member experience in recommendations sections
Emphasis on experience of family members or relatives	Those focusing on withdrawal of care
Emphasis on assisted suicide	Secondary source materials Those with emphasis on advance care directives or advance care planning Those with emphasis on suicide (not assisted suicide) Those with emphasis on CPR and DNR status Those with emphasis on hastening death of children with terminal illness Those with emphasis on organ donation Those with emphasis on continuous sedation

Final Inclusion/Exclusion Criteria [b]

Inclusion (also including above criteria)	Exclusion (also including above criteria)
Emphasis on the experience of family members or relatives in relation to a family member receiving assistance in dying	

Note. [a] Using Titles only; [b] Using Abstracts and Full-Text when needed.

APPENDIX C

PRISMA Chart

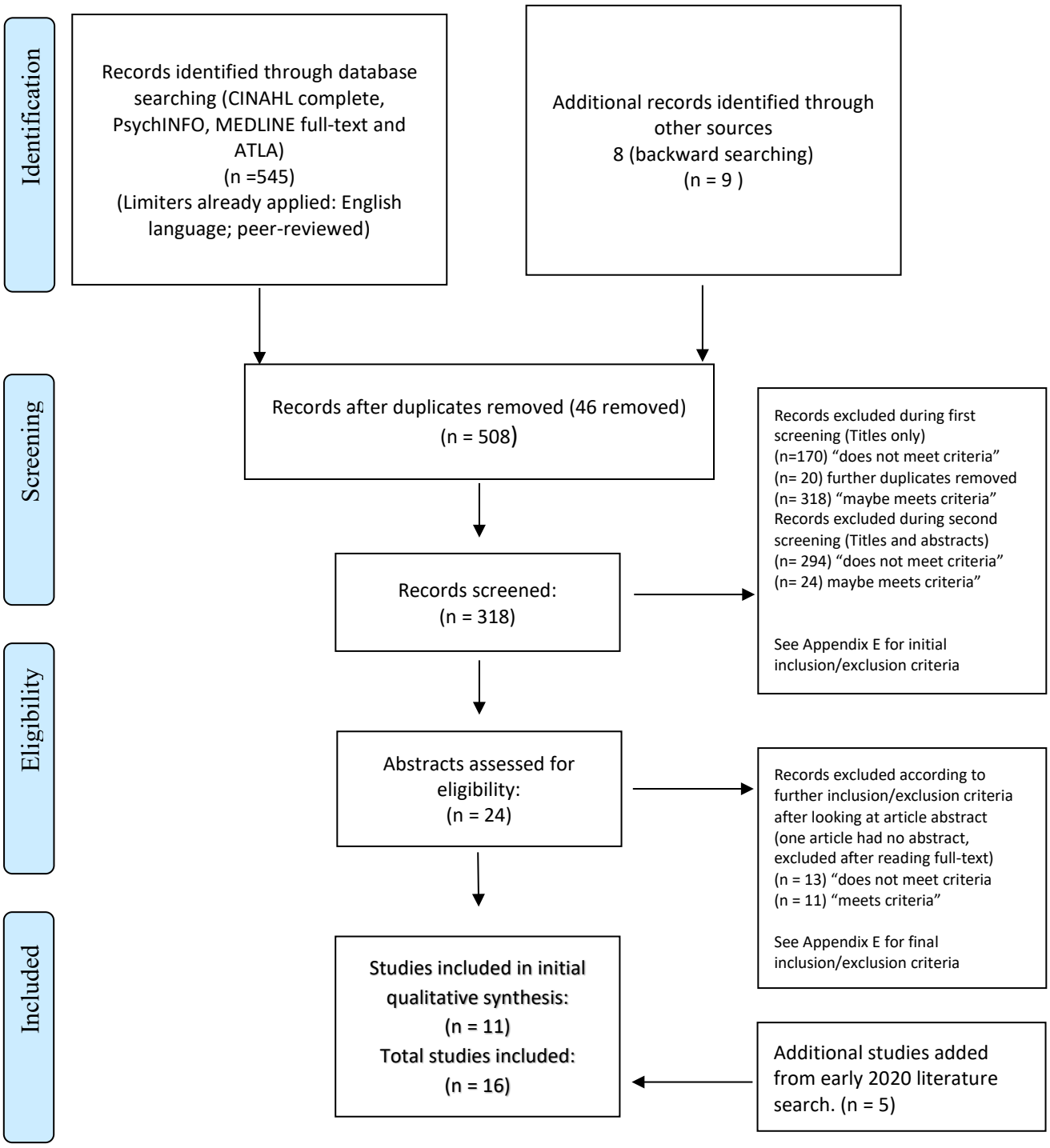
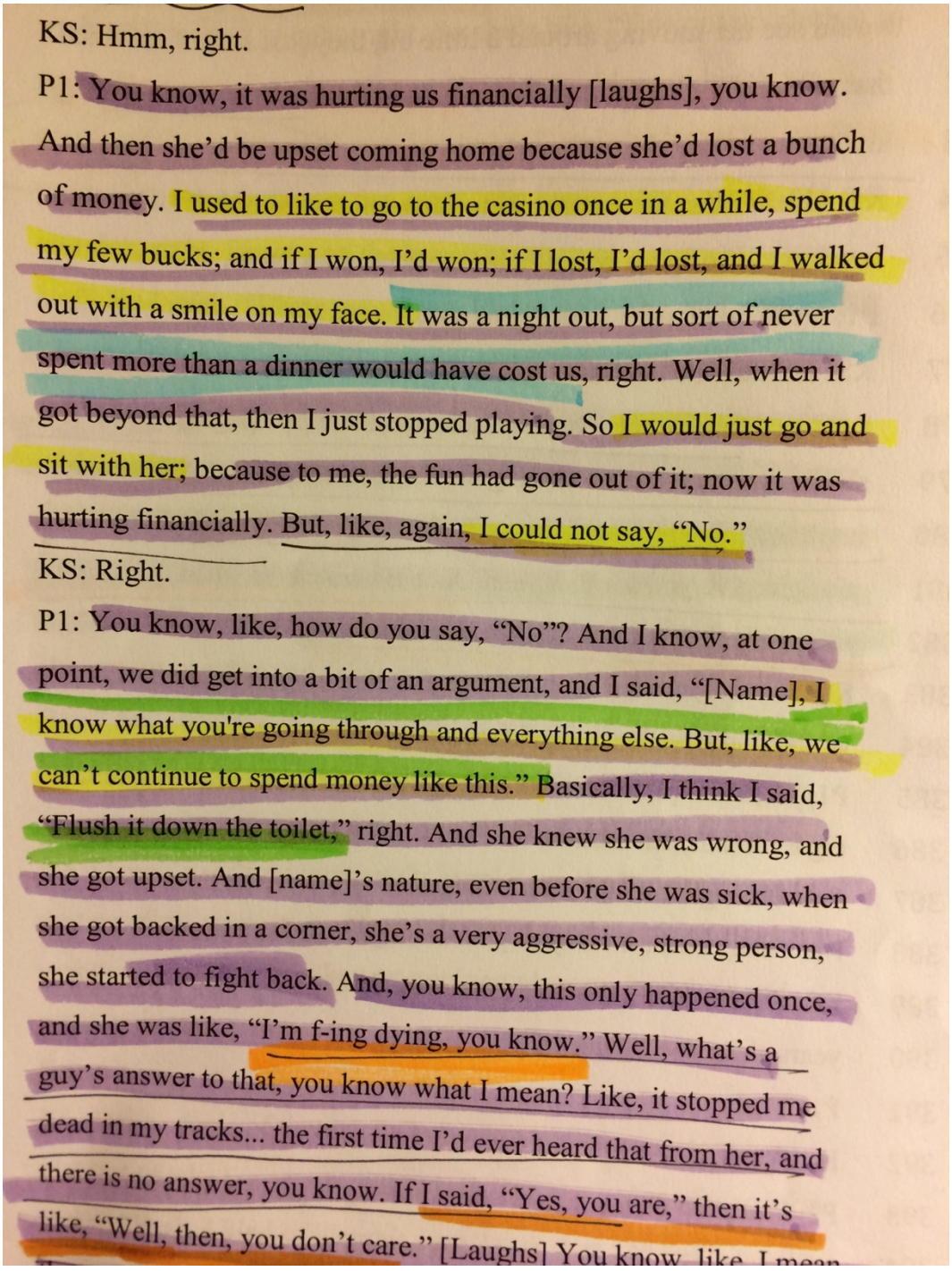


Figure B1. PRISMA chart. Adapted from D. Moher, A. Liberati, J. Tetzlaff, D. G. Altman, the PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA

APPENDIX D

Coloured Example of Highlighted Voices



KS: Hmm, right.

P1: You know, it was hurting us financially [laughs], you know. And then she'd be upset coming home because she'd lost a bunch of money. I used to like to go to the casino once in a while, spend my few bucks; and if I won, I'd won; if I lost, I'd lost, and I walked out with a smile on my face. It was a night out, but sort of never spent more than a dinner would have cost us, right. Well, when it got beyond that, then I just stopped playing. So I would just go and sit with her; because to me, the fun had gone out of it; now it was hurting financially. But, like, again, I could not say, "No."

KS: Right.

P1: You know, like, how do you say, "No"? And I know, at one point, we did get into a bit of an argument, and I said, "[Name], I know what you're going through and everything else. But, like, we can't continue to spend money like this." Basically, I think I said, "Flush it down the toilet," right. And she knew she was wrong, and she got upset. And [name]'s nature, even before she was sick, when she got backed in a corner, she's a very aggressive, strong person, she started to fight back. And, you know, this only happened once, and she was like, "I'm f-ing dying, you know." Well, what's a guy's answer to that, you know what I mean? Like, it stopped me dead in my tracks... the first time I'd ever heard that from her, and there is no answer, you know. If I said, "Yes, you are," then it's like, "Well, then, you don't care." [Laughs] You know, like, I mean

APPENDIX E

Introductory Email Script

Dear_____,

Thank you inquiring about this research project. The purpose of this study is to explore how family members experience Medical Assistance in Dying (MAiD), and consider the implications for nursing practice. Though MAiD has been legalized and implemented across Canada since June of 2016, no studies have explicitly examined how family members might experience the processes, procedures and policies surrounding MAiD. This study aims to hear from the various perspectives of family members who have had a loved one receive MAiD, in order that health care professionals can better support families throughout the process.

Participants in this study will have had a loved one receive MAiD in Canada, and will be 19 years or older. If you meet this criteria, and are interested in participating, I would love to hear from you and arrange a brief pre-screening telephone interview. This phone call provides an opportunity for you to ask further questions about the study prior to agreeing to participate. It also helps us together evaluate if participating in this study might be helpful to you in this time of loss. If you agree to participate after the pre-screening telephone interview, and meet the eligibility criteria, we will set up a 45-60 minute face-to-face or telephone interview for a mutually agreeable time and location.

Thank you again for your interest in this study, and please do not hesitate to contact me for further clarification. If you are interested in being a participant, please respond by email or telephone indicating this, and we can arrange to have a pre-screening telephone interview.

Sincerely,

Kelly Schutt

APPENDIX F

Pre-screening Sample Telephone Script

Begin with introduction of who I am and explain that I am returning his or her call regarding participating in the family bereavement study. Thank participants for their interest in this study.

"The purpose of this call is to explain the study to you, answer any questions you may have and to determine whether there is any reason not to participate in the study. There is potential for this phone call to take several minutes. Is it all right to proceed or would another time be more suitable?"

"I want to make sure that you fit the criteria for inclusion in the study, and together determine if participating in the study would be a good fit for you. In order to do this, I have a few questions for you. None of the information you share with me now will be stored or recorded."

Semi-structured questions:

"As you might've seen in the email I sent you about the study, my thesis is looking at the experience of family members whose loved one has received Medical Assistance in Dying, or MAiD."

INCLUSION CRITERIA: LOVED ONE & MAID.

Have you had a loved one receive MAiD in Canada? (wait for response; if "yes", continue; if "no", thank the individual, and explain that this study is focusing on hearing from family members who have had a loved receive MAiD, and end phone call).

EXCLUSION CRITERIA: PSYCHOSIS SYMPTOMS/SUICIDE RISK.

[the following questions are intended to prompt conversation that would elicit evidence of psychotic symptoms or recent/current suicidal ideation]:

Can you tell me a bit about your bereavement experience? How did you cope initially with the death of your loved one? What is it like now? [listen for evidence of psychotic symptoms such as withdrawal from others, delusions or hallucinations, high anxiety or depression, suspicion, disordered speech)

Has there ever been a time when you sought medical or counselling assistance to help you cope with your grief? What were the reasons for seeking such assistance? [listen for evidence of psychotic symptoms such as withdrawal from others, delusions or hallucinations, high anxiety or depression, suspicion, disordered speech)

Have you experienced a psychiatric crisis (e.g., called a crisis line, seriously contemplated suicide) since the loss of your loved one? If so, when did this take place? How are you doing now?
If the potential participant indicates that s/he is presently suicidal, the screening portion of the call will be terminated immediately as the potential participant will not meet the requirements of the study. Instead, the researcher will conduct a brief suicide risk assessment and direct the potential participant to the appropriate level of care.

Questions that may facilitate such a risk assessment include:

1. *Have you ever attempted to hurt myself or tried to commit suicide in the past?*
2. *How often do you presently think of harming yourself?*
3. *Do you presently have a plan or a timeframe to harm yourself?*
4. *Has anyone in your family or among your friends committed suicide or attempted to harm themselves in the past?*

If the potential participants indicates that s/he is at a greater risk for suicide (e.g., is thinking about suicide daily, has a current plan/timeframe for committing suicide, has recently attempted suicide), the participant will be encouraged to call a suicide hotline (e.g., 1-800-SUICIDE 784-2433) and will be given the information of their local public mental health centre (e.g., Abbotsford Mental Health; 604-870-7800). In the event that this potential participant has a mental health provider, s/he will also be directed to contact him or her. In the event that a potential participant is actively suicidal during the telephone screening call (i.e. indicates that s/he plans to commit suicide), the potential participant will be required to seek professional help immediately (eg. call his/her doctor, psychiatrist, counsellor, or 911).

To conclude this pre-screening interview, proceed to ask if the participant feels comfortable to proceed. Discuss a mutually agreeable time and location for the interview. Explain that the researcher will now send an informed consent form that the participant can review and bring with them to the interview.

Ask if there any final questions that they would like to ask.

APPENDIX G

Semi-Structured Interview and Topic Guide

Introductory comments:

Thank you for being willing to share your experience with me today. As we've talked on the phone briefly about prior to today, my thesis is exploring how family members experience the process of their loved one receiving MAiD. I can imagine that it is very difficult to reflect on this experience and to share those reflections. I'm so honoured to hear your story, and want you to feel free to share as much as you feel comfortable with. I have some questions that I've prepared, but really, I am interested in hearing what it is that you'd like to tell me. At any point, we can pause the interview, or end it. Or, if there's a question you'd rather not discuss, that's okay too. Do you have any questions for me before we begin?

Topic Guide:

1. Can you tell me about _____? (*ask to see photo of loved one, if they chose to bring one).*
2. How would you describe your relationship with _____?
   Prompts:
   a) What was it like for you, when _____ first mentioned MAiD? *(focus on experience: where were they, who was there, how were they told, where in the illness trajectory was the family member at?)*
   b) Did the request surprise you?
3. How would you describe your involvement in the process of _____ receiving MAiD?
   Prompts:
   a) Did you feel any inner tension about being involved with MAiD? Did this change over time?
   b) Did you feel any relational tension as a result of your involvement/lack of involvement with MAiD?
   c) Were you part of the decision-making process? *(focus on how were they involved; what is like for them to be involved, or not be involved; did they feel that their values and beliefs were welcome?)*
   d) Were you present at the time of death? What was that like for you?
4. How do you think _____'s decision to pursue MAiD might have impacted your final days/weeks/months with them?
   Prompts:
   a) Did you feel that MAiD allowed you more of an opportunity to discuss dying with _____?
   b) Do you think MAiD provided more opportunity to say goodbye?
   c) Did you experience any added burdens or challenges in this time, as a result of _____'s decision to receive MAiD?

5. As you reflect on the time that has passed since _____ died, how do you think your experience with MAiD has impacted your grief process?
   Prompts:
   a) What supports have been most helpful to you during this time?
   b) Did you receive any aftercare or bereavement support? Was this helpful?
   c) Have you experienced feelings of relief? Feelings of regret? Feelings of peace? Feelings of distress?
6. As you reflect on the experience of _____ receiving MAiD, do you have any insights for healthcare professionals or health policymakers? Nurses?
   Prompts:
   a) What was most helpful to you during the process of MAiD?
   b) What was most difficult for you about the process of MAiD?
7. As we conclude our time together, is there anything else you'd like to tell me more about?
   Prompts:
   a) How are you doing?

APPENDIX H

Informed Consent

PURPOSE OF THE STUDY

Since June 17, 2016, Canadians have been able to request and receive assistance in dying. The impact of Medical Assistance in Dying (MAiD) on family members is an important consideration, especially in knowing how to best support families.
The **purpose** of this study, therefore, is to explore how family members experience MAiD and consider the implications for nursing practice.

PROCEDURES

If you choose to participate in this study, you will be asked to review and sign this informed consent and complete a participant profile. You will have the opportunity to share your experience of having your loved one receive MAiD. Your responses will be recorded on a digital voice recorder. It is estimated that you will need to set aside approximately 1.5 hours of your time for completing the entire study. Approximately 45- 60 minutes of this time will be devoted to the interview itself. After the interview, the researcher will debrief the interview experience with you, and respond to any questions or concerns you might have. There may be a brief follow-up interview to clarify responses and validate my interpretations.

POTENTIAL RISKS AND DISCOMFORTS

During this study, you will be asked questions that will invite you to share your personal experience related to having your loved one receive MAiD. Some of these questions may be difficult or painful to answer. If you experience emotional discomfort during the interview, please let the principal investigator know. You may choose not to answer a question, and you are free to end the interview at any time or continue it at a later date. You may also withdraw from participation entirely. If needed, you are encouraged to contact a counsellor. The researcher can provide you with a list of counsellors whom you may contact for further support.

POTENTIAL BENEFITS OF PARTICIPATION

Direct Benefits. You may find that talking about your experience is a helpful process and that sharing your experience is meaningful in your time of loss. It may also be comforting to you to know that your experience could indirectly benefit other families, as policies and procedures surrounding MAiD are implemented across Canada.

Societal Benefits. The findings from this study will contribute to what is currently a small body of knowledge on how family members experience MAiD in Canada.

CONFIDENTIALITY AND ANONYMITY

Any information that you share during this entire study will remain confidential. To preserve your anonymity, research forms, such as this informed consent, will not be stored with the audio recording or the transcript of the interview. Recorded interviews will be transcribed and identifying details such as names of persons, organizations, or cities will be removed. The only exception to this is if you request that researchers use your loved one's name in loving memory. Direct quotations and/or summaries of your experiences may be used in the final research report to provide readers with a rich description of your experience. Thesis supervisors and fellow graduate students assisting with data analysis will receive these anonymized transcripts. Thesis supervisors will also have access to your informed consent, participant profile, and debriefing form to ensure the integrity of the research process.

DATA: STORAGE AND RETENTION

Storage. The interview's recording and de-identified transcripts will be saved on an secure, password-protected online storage space called OwnCloud. A copy of this informed consent form, and your participant profile will also be retained. These documents will be stored separately in locked filing cabinets so as to preserve your anonymity.

Retention. All data will be destroyed after five years from the defense date. Anonymized data may also be used for future research if you give consent and REB gives approval to conduct the research.

COMPENSATION

There is no remuneration or compensation for participation in this study.

QUESTIONS OR CONCERNS ABOUT STUDY

If you have any questions or concerns about the study itself, you may contact:

Kelly Schutt
Principal Investigator
Kelly.schutt@twu.ca

Or, you may also contact the principal investigator's supervisor:

Sheryl Reimer-Kirkham, PhD, RN
Professor, School of Nursing
Trinity Western University
Sheryl.kirkham@twu.ca

CONTACT FOR CONCERNS ABOUT YOUR RIGHTS AS A PARTICIPANT

If you have any concerns about your treatment or rights as a research participant, you may contact:

Elizabeth Kreiter
Research Ethics Board Coordinator, Office of Research
Trinity Western University
604-513-2167
elizabeth.kreiter@twu.ca

WITHDRAWING FROM THE STUDY

To withdraw from the study, please contact the principal investigator. You do not need to give a reason for your withdrawal. There are no penalties for withdrawing from the study. If you choose to withdraw from the study, a signed copy of this informed consent will be retained securely. Audio recordings and transcripts will be destroyed. Your data will be removed from the research report and from research notes.

CONSENT

Your signature below indicates that:

- You consent to participate in this study.
- You understand the risks and benefits of participation.
- You understand that your responses will be kept confidential.
- You understand that the principal investigator will take steps to protect your anonymity during the research process (cross out if you would like your loved one named).
- You understand that you may withdraw from the study at any time up until the final report is submitted to the Masters of Science in Nursing department for a defence. You do not need to give a reason for your withdrawal.
- You have had your questions about the study answered to your satisfaction.
- You have received a copy of this consent form for your own records.

Printed Name of Participant	*Signature*	*Date*
Printed Name of PI	*Signature*	*Date*

PERMISSION TO CONTACT

I would like a copy of the final research report.	☐ Yes ☐ No
I am willing to be contacted by the principal investigator if there are questions or things that need clarification.	☐ Yes ☐ No
I am willing to review and provide feedback on a summary of the findings	☐ Yes ☐ No

ACKNOWLEDGEMENT

I have had any questions or concerns answered by the principal investigator. I understand that I can contact the principal investigator if I have additional questions or concerns, wish to review the summary and interpretation of the findings, or wish to withdraw from the study.

I have also indicated my preferences for being contacted after this interview and understand that I can change my preferences at any time by contacting the principal investigator.

Printed Name of Participant	*Signature*	*Date*
Printed Name of PI	*Signature*	*Date*

APPENDIX I

Participant Debriefing

Thank you for participating in this study. Your willingness to share of your experience with Medical Assistance in Dying is greatly appreciated. The findings from this study will contribute to a body of research and theory on the experience of MAiD for family members.

If you have experienced distress after sharing your experiences during this research interview, you may want to consider speaking with a counsellor. The principal investigator can provide you with the names of counsellors who may be willing to meet with you should you find additional support helpful.

As a reminder, although we have finished with the interview, your involvement in this study is still voluntary and you may withdraw from participation up until the thesis is submitted for internal defence to the Masters of Science in Nursing department at Trinity Western University. The internal defence is expected to occur the fall of 2018. To withdraw from the study, please contact the principal investigator. You do not need to provide a reason for your withdrawal. There is no penalty for withdrawing from this study.

QUESTIONS OR CONCERNS?

If you have any questions or concerns or wish to withdraw from participation, you may contact:

Kelly Schutt
Principal Investigator
Kelly.schutt@Twu.ca

If you have any concerns about your treatment or rights as a research participant, you may contact:

Elizabeth Kreiter
Office of Research,
Trinity Western University
604-513-2167
elizabeth.kreiter@twu.ca

PERMISSION TO CONTACT

I am willing to be contacted by the principal investigator if there are questions or things that need clarification. ☐ Yes ☐ No

I am willing to review and provide feedback on a summary of the findings ☐ Yes ☐ No

ACKNOWLEDGEMENT

I have had any questions or concerns answered by the principal investigator. I understand that I can contact the principal investigator if I have additional questions or concerns, wish to review the summary and interpretation of the findings, or wish to withdraw from the study.

I have also indicated my preferences for being contacted after this interview and understand that I can change my preferences at any time by contacting the principal investigator.

Printed Name of Participant	*Signature*	*Date*
Printed Name of PI	*Signature*	*Date*